DOCUMENT RESUME

ED 236 883 EC 161 104

AUTHOR	Del Polito, Carolyn M., Ed.; Barresi, Josephine G., Ed.
TITLE	Alliances in Health and Education: Serving Youngsters with Special Needs [and] Instructor's Guide.
INSTITUTION	American Society of Allied Health Professions, Washington, D.C.
SPONS AGENCY	Office of Special Education and Rehabilitative Services (ED), Washington, DC.
PUB DATE	83
GRANT	451-CH-00233
NOTE	360p.
AVAILABLE FROM	American Society of Allied Health Professions, One Dupont Circle, Suite 300, Washington, DC 20036 ($15.00 set; $12.95 member; add $2.50 for first class postage and handling).
PUB TYPE	Guides - Non-Classroom Use (055)
EDRS PRICE	MF01/PC15 Plus Postage.
DESCRIPTORS	*Allied Health Occupations; Child Advocacy; Communication Skills; Delivery Systems; *Disabilities; Federal Legislation; Nurses; Physicians; *Professional Occupations; Social Workers; *Staff Role; Therapists

ABSTRACT

The text examines issues in the roles of allied health professionals serving disabled children and youth. An introduction by C. Del Polito reviews the effects of negative public attitudes toward people with disabilities and describes an advocacy project to serve allied health professionals. In unit 1, J. Barresi traces the history of public policy regarding children with handicaps, describes the differences between federal and state law, and considers the future of P.L. 94-142, the Education for All Handicapped Children Act, in light of court rulings and actions by the Reagan administration. A. Bashir examines the roles and responsibilities of health professionals in serving handicapped children and youth in unit 2. Emphasis on the importance of communication as a competence for allied health professionals is addressed and suggestions for improving communication are presented by C. Del Polito in the third unit. Screening, assessment, planning and review of educational and health related services are focused on by A. Bashir in unit 4, with a section listing the definition, high risk indicators, behavioral indices, classification considerations, assessment issues, and intervention aspects for a variety of handicapping conditions. Strategies for referral, coordination, and management of services are considered in a chapter by J. Wittenmyer. Advocacy is the topic of the final chapter written by E. Ellis. Individual and collective advocacy are reviewed as are resources for effective advocacy. Appended information includes selected P.L. 94-142 regulations and a listing of national and federal organizations and groups. An accompanying instructor's guide presents guidelines on preparing for and presenting a workshop on the text. Suggested questions and exercises for each of the text's units are presented, as are transparencies and sample handouts. (CL)

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ALLIANCES IN HEALTH AND EDUCATION:

Serving Youngsters With Special Needs

Carolyn M. Del Polito
and
Josephine G. Barresi
Editors

EC 161104

1983
The American Society of Allied Health Professions
One Dupont Circle, N.W., Suite 300
Washington, D.C. 20036

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Cover photo: Marty LaVor © 1983.

This publication is based upon work performed pursuant to Grant No. 451 CH 00233 from the Office of Special Education and Rehabilitative Services, U.S. Department of Education. The points of view expressed herein are the authors and do not necessarily reflect the position or policy of the U.S. Department of Education.

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ABOUT ASAHP

The American Society of Allied Health Professions (ASAHP) is a national nonprofit scientific and professional organization formed to serve the needs of allied health educators, practitioners, professional institutions and organizations, and others interested in improving health care and health-care education. ASAHP has as its ultimate goal the best possible training and utilization of all allied health professionals. As a means to that goal, the Society provides a vital forum in which allied health educators and practitioners--their educational and clinical institutions and their professional associations--can address and act on mutual concerns.

Established in 1967, ASAHP now serves 118 educational institutions, 23 national professional organizations, and over 1,300 individual members.

The Society's role in serving the interests of these constituent groups is twofold. First, it provides a forum for sharing concerns and solutions that relate to significant, mutually relevant allied health issues. Second, ASAHP serves as the vanguard of the allied health movement--an organization which forcefully and effectively represents positions of overreaching allied health significance to government, other major health-education and health-care system elements, and the public.

ASAHP's office headqurters are located at One Dupont Circle, N.W., Suite 300, Washington, D.C. 20036. Telephone (202) 293-3422.

No one seems to be concerned about what I will do with my life. As though now I have an excuse for not giving or sharing or searching for purpose in life. Is being blind what I am "to do?"

Suddenly I'm different, not Susan any more, . . .
Suddenly my friends perceive me as a crystal doll
Too delicate, too fragile to be touched.
Afraid they may upset me; they step back,
Choose words with care,
And put me on the shelf I hate so much.
I'm still me looking out,
But what do they see looking in? . . .
Are they blind, why can't they see me?
Must blindness always come before my name?

I am not a blind person; I am a person who happens to be blind.

Susan Dunn, 1980

ACKNOWLEDGMENTS

The editors gratefully acknowledge the assistance of the many individuals who made this publication possible. Along with Advisory Council members who assisted in the conceptualization of the content issues addressed throughout the project, we wish to thank the many guest faculty, resource persons, parents, consumers, and health and education professionals who participated in ASAHP's regional workshops across the country, testing and shaping the material contained in these pages.

Most especially, we are grateful to **Anthony S. Bashir**, **Ethan B. Ellis**, and **Jayn Whittenmyer**. As authors for this publication, as advisors, and as major faculty for the Society's regional workshops, they have been a source of inspiration, humor, and expertise during the past three years.

In addition, we wish to acknowledge the following individuals who reviewed the manuscripts with care and patience and provided critical comments on unit contents: **Katherine G. Butler**, Director, Special Education and Rehabilitation, Syracuse University; **David Guy**, Director of the Physical Therapy Department at Vanderbilt University Hospital; **Polly A. Fitz**, Dean, School of Allied Health Professions, University of Connecticut; **Gwendolyn Talbot**, President and Founder of Chronic Pain Outreach; and **Fred Weintraub**, Director of Governmental Relations at the Council for Exceptional Children. Finally, we wish to thank ASAHP staff and **Stanice Grandy**, Project Administrative Assistant, for long hours of production.

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INTRODUCTION

Carolyn M. Del Polito

. . .
Let it be a son, a son, said
the man in the driving mirror.
Let it be a son . . .

At seven-thirty the visitors'
bell scissored the calm of the
corridors, The doctor walked
with me to the slicing doors.

His hand upon my arm, his voice
— I have to tell you — set
another bell beating in my head:
your son is a mongol the doctor
said . . .

from "The Almond Tree"
by John Stallworthy*

---

*From **The Astronomy of Love**, Oxford University Press, 1961.

A child is born with a disability. Where, when and how do service providers in health and education enter the picture? As professionals or as concerned citizens and neighbors, what assistance or interventions can professionals provide for the parents and the child to ensure the child moves through the educational and related-health services maze and is educated appropriately to lead the fullest and most productive life possible? What preparation do service providers need to fulfill their professional and personal roles and responsibilities for youngsters with disabilities and their families?

The Education for All Handicapped Children Act of 1975 (Public Law 94-142) guarantees all children and youth between the ages of three and 21 with handicapping conditions a free and appropriate public education in the least restrictive environment. Funding provided under the authority of Public Law 94-142 has helped prepare related-service and special education professionals to meet the new requirements of the law, particularly in the identification of children and youth with disabilities and the delivery of special education and related services.

Despite the passage of this law, however, large numbers of American youngsters with handicapping conditions still are not receiving appropriate services. While some health care providers, most notably audiologists, occupational and physical therapists, and speech-language pathologists, have long been involved in identification, referral, and advocacy initiatives for children and youth with disabilities, most of the other health professionals have not.

The American Society of Allied Health Professions (ASAHP) believes all health professionals, including those who work in health-care settings, have special access to the majority of these children and the systems which serve them. These professionals can impact local, state, and national efforts in identifying and referring children and youth with handicapping conditions for appropriate services. Further, they can help to advocate on their behalf.

Supported by the U.S. Education Department's Office of Special Education and Rehabilitative Services (OSERS) through the Education for All Handicapped Children Act of 1975 (Public Law 94-142), the American Society of Allied Health Professions initiated a three-year national project in 1980 to address these and other issues related to a major policy concern affecting the allied health professions--facilitating alliances among health and education professionals to address the unmet education and related-health needs of youngsters with disabilities. The Society's promotion of "alliances" has involved all the related-health professions, not merely those, like occupational and physical therapists, whose work regularly involves persons with handicapping conditions. The Society's initiative has involved such others as physician and nurse assistants, dental hygienists, nutritionists, and medical records professionals whose health care roles bring them into regular, often very early, contact with children with handicaps.

All health professionals may not possess the appropriate expertise to assist clients, families, or friends with problems related to the educational and health-related needs of youngsters with disabilities. As professionals in the health-care system, however, they all will be perceived to possess such competence and need to be prepared. The challenge of ASAHP's initiative, therefore, has been to design curricula, instructional strategies, and advocacy models which prepare health professionals for their expanding roles and responsibilities for youngsters with disabilities and their families.

Through the support of OSERS and ASAHP's networks, the Society has initiated a number of innovative activities in the coordination of training and service delivery. This publication, **Alliances in Health and Education: Serving Youngsters With Special Needs**, is an outgrowth of these activities. The American Society of Allied Health Professions is pleased to provide this publication for all professionals in health and education concerned with meeting the needs of youngsters with disabilities and their families.

PRIORITY: COLLABORATION

Outcomes of the Society's current project have pointed continually to the critical need for an integrated, coordinated service delivery system composed of providers who view youngsters with disabilities as whole persons with unique, life-long health and education needs. Similarly, the competition for limited resources at all levels of government demands the maximal, appropriate use of all available human and fiscal resources. More than ever, efficient, cost-effective **coordination** of health and education services must be provided.

Case after case of children and youth with handicaps or chronic illnesses clearly illustrate the need for coordinated service delivery mechanisms. Consider the case of a three-and-a-half year old boy born with rubella syndrome who received services from 13 different agencies and clinics (Barba, 1977). Along with congenital heart disease and congenital cateracts, the child exhibited slow motor and mental development, blindness, hearing loss, and intolerance to milk. By three-and-half years of age, this youngster and his family had interacted with medical, related health, and education professionals representing approximately 20 different professions.* Barba reports:

---

*Professionals serving this child could include: pediatrician, psychologist, social worker, nurse, ophthalmologist, allergist, audiologist, otolaryngologist, speech-language pathologist, pediatric neurologist, occupational therapist, learning disabilities specialist, nutritionist, clinical laboratory practitioners, cardiologist, physical therapist, optometrist, medical assistant, medical record administrator, and physician assistant.

> . . . the family of this child is being run to death and has incurred considerable expenses despite multiple resources for assistance. Virtually, without a break, this mother has continuous appointments over two week periods. . . .
>
> This child has received regular follow-up for his various diagnostic problems. However, his family is run ragged and so near the end of its rope that they are considering institutional placement despite the inappropriateness of such placement. . . .
>
> Many of the services given this child grew. . . . Countless medical summaries and notes exist but they are scattered in the records of several facilities (p. 203).

This "patchwork" of narrowly focused approaches to service delivery, which tends to be based on age, disease or handicap classification, income, political jurisdiction, and specialization of the service provider, "multiplied by millions is an estimate of the cost in lives, energy, and effort that is spent with, in many instances, no gain for the . . . individual, his family, [or] society" (Barba, 1977, p. 203).

While specialized services are needed to meet the needs of persons with handicaps and their families, the professional parochialism or "narcissism" (Bashir, 1981) which has accompanied the growth of specialized services has supported inefficiencies in the delivery of services, including duplication of services, wasted resources, and competition among providers (Helge, 1981). Professional parochialism, which permeates the delivery system, generates additional barriers to cost-effective, quality care, including:

- Communication problems and mistrust among professionals, between professionals, youngsters, and their parents, and between and among programs, departments, and agencies;
- Lack of knowledge related to all handicapping conditions and other professionals' roles in serving persons with handicaps, thus promoting inappropriate diagnostic, case management, and programmatic strategies;
- Disparity in treatment, programmatic, and financial priorities; and
- Maintenance of perjorative attitudes toward youngsters with disabilities (Del Polito, 1982).

Effects of Attitudes and Labels

The last barrier identified above, **perjorative attitudes**, is seen by persons with disabilities as the major impediment in their lives to receiving health and education services. Although attitudes of Americans toward persons with disabilities generally tend to vary depending upon age, education, and socio-economic status, studies over the past forty years indicate surprising consistencies. According to Yuker (1981), most people have similar attitudes toward all persons with disabling conditions regardless of the person's specific impairment. Further, even though "more than fifty percent of the people in the United States publically express positive attitudes toward disabled persons, most people perceive handicapped persons as in some way different and inferior" to able-bodied individuals (p. 2-3). The resulting discrimination has been likened to the discrimination and oppression imposed upon racial, ethnic, and other minority groups, limiting the individual's potential as a participating member of mainstream society (Bogdan and Biklen, 1977; Telford and Sawrey, 1981; Gliedman and Roth, 1981; Shaver and Curtis, 1981).

This discrimination, or "handicapism" as defined by Bogdan and Biklen (1977), emanates from stereotypes and prejudices, and is evidenced throughout the structure of society: in personal interaction, in health and education policies and practices, and in the media which represents the larger society.

Through legislative, judicial, and executive actions, issues such as human dignity, right to individualized treatment, and provision of services in the least restrictive environment have been reinforced. The movement toward full physical and social integration of persons with disabilities into mainstream society, however, has been limited. They still are prevented from full access to society: in physical accommodations, in education, in employment, and in relationships.

As the myths and stereotypes which influence attitudes about persons with disabilities are examined, a major model in **defining** or identifying persons with handicapping conditions repeatedly emerges; that is, the medical model of **disease.** In their powerful book, **The Unexpected Minority: Handicapped Children in America**, Gliedman and Roth (1980) provided a detailed account of how an individual's perceptions of--and interactions with--persons with disabilities are conditioned by society's definition of a "handicap" as "disease" (pp. 18-27). As the authors note:

> In a first encounter the knowledge or perception that a person is handicapped is among the most important clues that we can obtain about his character. Indeed, in many instances the sudden discovery that the person is or is not handicapped suffices to transform our perception of his social **persona** completely (p. 19).

As all too many persons with disabilities will confirm, they are defined by their visible (or invisible) impairment. "Unlike temporary injuries, a handicap is considered by others to be integral--'essential'--to the handicapped person's social being" (Gliedman and Roth, p. 20). The person will be treated differently and will be expected to behave differently as well. Even with an invisible impairment (e.g., epilepsy, heart problems, or a mild retardation), the person is labeled with a **stigma**, "an undesired differentness," and finds him or herself at a distinct social disadvantage (Goffman, 1963).

Thus, once an impairment is diagnosed (labelled and categorized), a treatment model is prescribed and accepted by all--patient, family, and service providers. Reactions and interactions with the "diseased" person become treatment-oriented, focusing only on the impairment--the paralyzed leg, the learning disability--with little concern for the person who "owns" the paralyzed leg or the learning problem; thus confirming the person's **non-identity**.

While supported and reinforced by the norms of society, defining persons by their differences (their disabilities) is a critical indictment against both the health and education professions. Members of ASAHP's Interdisciplinary Task Force identified and emphasized a similar charge:

> Attitudes of health and education professionals working with persons with disabilities are more discriminatory than other persons not so involved. Health professionals, particularly, tend to perceive the youngster only in relation to the disability; not as a whole person (Del Polito, 1983, p. 3).

Other stereotypical attitudes, but logical outcomes, promoted by the disease model have been reiterated continually in print and nonprint media alike--from pre-school publications and comic books to newspaper accounts and horror films. Persons with disabilities are shown in the media as: (1) deviant, abnormally bad and repugnant, and therefore, essentially evil (i.e., diseased); (2) idealized and abnormally good, leading to unrealistic and abnormally high expectations of the individual (i.e., superhuman); (3) primarily dependent on others, requiring "special attention, special facilities, and special support," with little emphasis on the person's ability to cope or to make positive contributions to society; (i.e., dependent and dehumanized); and (4) deviant and strange, and "bizarre and anti-social" (again, deviant) (Yuker, 1981; Donaldson, 1980; and Biklen and Bogden, 1978).

Perhaps most damaging has been the presentation of disability as central to the plot or the character's role, reinforcing the inability of the person with a disability to participate fully in everyday life--the non-identity stereotype prevalent in American culture, even among the helping professions.

To counteract stereotyping behaviors, advocates in the disability rights movement have focused to a great extent on the effect of **language** on people's perceptions (able-bodied and disabled alike), and, therefore, on attitudes of persons with handicapping conditions.

> Visualize the difference between a person confined to a wheelchair compared to a person who uses a wheelchair. Confinement implies "restriction," or "imprisonment" or "restraint" where use signifies "control for a purpose" or "extension of ability." In a similar fashion, conjure the image of a person **suffering** from epilepsy rather than subtler words such as experiences seizures (Mullens, 1979, p. 20).

The language used to discuss and describe persons with disabilities and their handicapping conditions many times includes unwanted generalizations, particularly with categories of handicapping conditions. "Speaking of people as 'handicapped' or 'the disabled' implies a monolithic group . . . . The use of categorical labels has several negative outcomes, but one of the most derogatory practices is to make those descriptors into nouns," (e.g., LD's, epileptics, CP's, trainables, and wheelchair people), therefore equating devaluation with individual differences (Mullens, 1979, p. 21).

Similarly, respect (or lack of respect) for persons with handicapping conditions is communicated through the labels, symbols, and images we use for depicting relationships among persons with and without handicaps. "Rather than doing for or to a person with handicaps, the emphasis of interaction should be on mutual interaction" and on the benefit of "open, respectful" encounters among individuals with varying physical, mental, and social abilities and characteristics (Mullens, 1979, p. 23).

Focusing specifically on labels, the Council on Interacial Books for Children (CIBC) urges avoidance of all terms which dehumanize or objectify persons with disabilities, characterize them as dependent or pitiable, or which perpetuate the myth that persons with disabilities are incapable of participating in the life of a community (Biklen and Bogdan, 1978, p. 8). As will be noted throughout this publication, and as emphasized throughout ASAHP's advocacy initiative, the effects of language on "persons with disabilities" has been a major underlying theme to enhancing the provision of services to youngsters and their families.

Understandably, controversy regarding acceptable terms exists even among the advocates for persons with disabilities. While "handicap" is rejected generally because of its historic connotations of beggars who held "cap in hand," it still appears consistently in legislation designed to protect individuals against discrimination and provide them with appropriate health and education services. For a number of years now, the term "exceptional" has been favored by some advocacy groups; for others, however, it is considered a euphemism (Biklen and Bogdan, 1978, p. 8).

"Disability" and "impairment," also used extensively, add to the definitional dilemma, particularly when one considers that health and education services for persons with disabilities as well as compensation for providing these services are tied to local, state, and federal definitions. As for others in our culture, policymakers are affected not only by advocacy groups, but also by intertwining connotative and denotative meanings which have evolved over years of prejudice and handicapism. Thus, while "defining" or labeling persons with handicapping conditions has ethical implications relevant to the promotion of values and attitudes of service providers, the process and outcomes of labeling also present economic and political implications relevant to society as a whole.

A good differentiation among the terms impairment, disability, and handicap is provided by Stevens (1962): whereas an **impairment** refers to the physical, mental, or psychological problem itself, a **disability** refers to the limited function or behavior directly or indirectly dependent upon the impairment. For example, an impaired hand (severed nerves or absence of fingers) would result in a similar disability (i.e., lack of digital dexterity with limitations in writing or typing) which may or may not result in a **handicap** for the individual. As Birch (1981) notes:

> A handicap is measured by the extent to which an impairment, a disability, or both get in the way of normal living, including acquiring an education. Handicap is highly personal, for it is the name for an individual's own reactions to the presence of an impairment or disability. The central concept of handicap is this: consists of the individual's ability to live with that interpretation. **Many** people have impairments and disabilities. **Only some** people are handicapped because of them (p. 40).

A definition which takes into account the person's functional abilities in relationship to his or her environment implies new and important perspectives for persons with disabilities in terms of treatment, service delivery, and compensation for the impairment, and in terms of daily interactions with others in the environment. There are also broad implications for those providing health and education services as well as for those establishing policies for service provision and compensation/reimbursement.

The ethical and moral conflicts generated by these barriers further complicate the provision of services. To alleviate these barriers and inadequacies in the provision of education and health services to youngsters with handicaps, parents, consumers, and leaders in both health care and education are calling for needed revisions in training programs which will prepare all service providers to provide integrated, coordinated services adapted to the unique, life-long needs of children and youth with handicapping conditions.

ASAHP's Project

The challenge of ASAHP's Advocacy Project, therefore, has been to design curricula, instructional strategies, and advocacy models which encourage all health professionals, their educational institutions, and their professional associations to become involved in promoting the rights and needs of youngsters with disabilities and their families.

Advocacy is used throughout this publication to mean **facilitating a continuum of services for clients and their families: from listening to their needs and concerns to promoting and implementing legislation on their behalf.** This definition has guided ASAHP's development of curricula and instructional strategies used in regional workshops and conferences nation-wide, stressing the importance of the health professionals' understanding of (a) the needs and rights of youngsters with disabilities, (b) referral sources and strategies, and (c) advocacy skills and strategies.

A major activity of ASAHP's Project has been the implementation of regional workshops, designed for cadres of experienced allied health professionals in different areas of the country. Participants for each of the six workshops* were identified by their professional organizations as leaders within their professions and targeted for their unique potential in affecting change both within and outside their work environments. In addition to the significant professional and personal alliances and advocacy initiatives developed during the workshops, a major outcome was the identification of specific roles and responsibilities all health professionals should assume-- whether or not they interact directly or consistently with youngsters who have disabling conditions.

Unit 2 contains a complete listing of these roles and responsibilities; among those repeatedly emerging, however, were those addressing **collaboration** and **communication** among health and education professionals to insure appropriate identification, referral, and advocacy efforts on behalf of the youngsters and their families. Specifically, in providing services to youngsters with disabilities, professionals should:

---

*Regional workshops were conducted in California, Minnesota, Maryland, Vermont, Tennessee, and Colorado. Individuals participating in workshops have represented the professions of Audiology/Speech-Language Pathology, Corrective Therapy, Dental Assistance and Dental Hygiene, Dietetics, Health Record Administration, Rehabilitation Counseling, Social Work, Nutrition, Occupational Therapy, Physical Therapy, Nursing, Physician Assistance, Psychology, and Recreational Therapy.

1. Help coordinate efforts of health and education services;

2. Understand other health and education service professionals' roles;

3. Work cooperatively with other professionals concerned with the services provided for children and youth with disabilities;

4. Actively participate in coordinated and adaptive health-care planning for the life span of the youngsters;

5. Promote excellence in the quality of service delivery for youngsters with disabilities among one's own and others' professions;

6. Promote interdisciplinary pre-service teaming opportunities; and

7. Promote advocacy initiatives on behalf of these youngsters with other professionals.

While a few training programs in allied health address these issues, most do not. Leaders of the related health and education professions generally recognize the lack of training their students receive to prepare them for meeting their responsibilities for youngsters with handicapping conditions. Further substantiation has come directly from practitioners across the country (Del Polito, 1982a). They concur with and reinforce ASAHP's underlying position and the foundation of this publication: related health professionals, including those working in health-care settings, possess (a) special access to children and youth with handicapping conditions; and (b) little, if any, preparation for meeting their roles and responsibilities to ensure that these youngsters obtain appropriate health and educational services.

The American Society of Allied Health Professions is pleased to provide this important publication for educators and practitioners in the related health and education professions who come in contact with children and youth with handicapping conditions on the job, at home, and in the community. It is hoped that this publication will assist in preparing professionals in health and education to work together as team members to create a better world for children and youth with disabilities.

On behalf of the Society and the Project's Advisory Council, I wish to thank all those involved in the preparation of **ALLIANCES IN HEALTH AND EDUCATION: SERVING YOUNGSTERS WITH SPECIAL NEEDS.** Most importantly, much gratitude is due our authors, Anthony Bashir, Ethan Ellis, and Jayn Wittenmyer, who, as project faculty and advisors, have shared their unique styles and personalities throughout ASAHP's three-year project, proving collaboration and team effort make substantial differences in quality training programs. Similarly, sincere thanks to Josephine Barresi, my co-editor, and Stanice Grandy, administrative assistant, for their dedication of time and eneregy in managing so many of the publication details to produce this final document. Finally, to all those who have contributed to the Allied Health Child-Find and Advocacy Project through their involvement in workshops, seminars, and conferences--as participants, resource persons, or presenters--we thank them for sharing their commitment to quality health and education services to youngsters with handicapping conditions and their families. Their concerns are contained herein.

cmdp

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UNIT 1

Legal Foundations

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UNIT 1: LEGAL FOUNDATIONS

PURPOSE AND OBJECTIVES

Purpose:

To review the development and requirements of public policy for the education of children and youth with handicapping conditions and the implications of this policy for health professionals.

Special Objectives:

At the conclusion of this unit, readers should be able to:

1. Discuss the development of federal and state public policy for the education of children and youth with handicapping conditions from an historical perspective, including legislation, litigation and regulation.
2. Identify the rights and protections contained in Public Law 94-142 (The Education for All Handicapped Children Act of 1975) and Section 504 of the Rehabilitation Act of 1973 for children and youth with handicapping conditions and their families.
3. Recognize the need to obtain current information about federal and state legislation and regulations affecting the education and related-health needs and rights of youngsters with disabilities.
4. Identify the differences that exist between federal and state policy and among the states regarding the provision of special education and related services to children and youth with handicapping conditions.
5. Identify their state's special education programs, policies and procedures for providing services to children and youth with handicapping conditions and their families.
6. Discuss the implications of Public Law 94-142 on the scope of practice for all health professionals.

UNIT I

Educating Children With Handicaps: A Legal Primer for Health Professionals

JOSEPHINE G. BARRESI

> . . .One afternoon in 1977 I sat with Peter Libassi, then Health, Education and Welfare's general counsel, listening to witnesses while we were considering pending regulations for Section 504 of the Rehabilitation Act, the section prohibiting discrimination against qualified disabled people. Among the witnesses was the mother of a disabled child from a nearby state.
>
> She told of her retarded daughter standing in the living room looking out the window as the school bus drove up their road, stopping to pick up other children. As the mother told us of her daughter asking each day why she could not go to school, the mother began to cry. So did the general counsel, so did I and, I believe, so did everyone else in that room. I have no wish to play that scene again, nor do the parents of handicapped American children. (Edwin W. Martin, first Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education)

The past two decades have borne witness to a wide breadth of social reform for persons with handicapping conditions. What once was called a "quiet revolution" (Dimond, 1973, Weintraub and Abeson, 1974) became a movement well recognized in state capitals, in courtrooms, and finally in the Congress of the United States itself. Centuries of rejection, discrimination, fear, pity, charity, and second class citizenship, slowly are giving way to equality and justice under the law. Architectural barriers are being removed. Transportation and housing are becoming accessible. Discrimination in employment is prohibited. Laws concerning zoning, voting rights, marriage, guardianship, institutions, and community services which discriminate against persons with disabilities are being rewritten.

It is in education, however, that the changes occurring are most far-reaching, for it is "by education that each of us...attains the full measure of the humanity we possess" (Pasham, 1981). Compulsory attendance laws that exempted children with handicaps have changed. Schools which denied education to children with disabilities are now providing services. Children who once were separated from their families and sent away to residential facilities for their education are now living at home and attending neighborhood schools.

With the passage of Public Law 94-142--the Education for All Handicapped Children Act of 1975--health and education services for youngsters with handicapping conditions have changed radically. Educational approaches and systems also have changed, powerfully affecting the youngsters, their families, their teachers, and other professionals who serve them. These changes in service delivery require professionals in education and related-health fields to assume new and expanding responsibilities which demand an understanding of the legal rights of children with disabilities and the procedures necessary to secure them.

In the pages that follow, a brief history of public policy for the education of children with handicapping conditions is presented; its current status described; and some future trends anticipated for health professionals and for the children they serve are suggested.

HISTORICAL BACKGROUND

Treatment of persons with handicapping conditions has changed dramatically from ancient times to the present. The early Greeks and Romans practiced infanticide and attempted to exorcise persons who were physically or mentally handicapped (Hewett and Forness, 1977). Plato and other philosophers are said to have believed that those persons born handicapped should be hidden away. Following the Renaissance period, the first attempts to educate persons with handicaps began to emerge. John Locke's "tabula rasa" theory in the 1600's --that all individuals are born into the world with the mind a clean slate before impressions are recorded on it by experience--set the stage for increased emphasis on training individuals to lead more productive lives. Although the treatment of individuals with handicapping conditions still took place in institutional settings, during the eighteenth and nineteenth centuries, rehabilitation of the individual rather than mere basic care began to be stressed. Techniques developed by such pioneers in the field of special education as Itard, Seguin and Montessori are still being used today.

As public education developed in the United States, it did so with an implicit rationale that manpower needed training in order for the industrial revolution to flourish. Those unlikely to be hired for positions in factories and steelyards and the like--minorities and the handicapped--did not need an education. Even with the increase in compulsory attendance laws, exemptions for the handicapped were the rule, rather than the exceptions. As a result, compulsory attendance laws in most states operated as non-attendance laws for youngsters with handicaps (Weintraub and Abeson, 1972). When students were found who were not functioning at an expected level, the tendency was to isolate them into alternative environments known as "special classes." This trend and continued institutionalization dominated educational practice until the mid 1960's. The current policy toward educating children with disabilities evolved out of the civil rights era of the sixties, following closely the pattern of equal educational opportunity lawsuits filed by Black Americans at that time.

The Education for All Handicapped Children Act of 1975, Public Law 94-142, represents a major shift in the education of children and youth with handicapping conditions. As national policy, it stands as a symbol of the change from custodialism to an emphasis on the development of the individual potential in each person (Merchant, 1979).

In the following sections, an examination of case law and state and federal antecedent legislation reveals the most recent origins of current education policy for persons with handicaps.

LANDMARK LITIGATION

Judicial action has played a critical role in the movement toward equality of opportunity for children, youth and adults with handicapping conditions. The late sixties and early seventies witnessed a flood of relevant lawsuits which impacted on the timing and substance of subsequent state and federal legislation, including Public Law 94-142. Precedent-setting cases from this period included Pennsylvania Association for Retarded Children (PARC) vs. Commonwealth of Pennsylvania, 1971, Mills vs. the Board of Education of the District of Columbia, 1972, Wyatt vs. Stickney, 1972, Welsch vs. Likens, 1974, Hobson vs. Hanson, 1967 and 1971, and Diana vs. Board of Education, 1970 and 1973. These suits addressed--for the first time--(a) the lack of educational opportunities for children and youth with handicapping conditions, (b) the denial of appropriate treatment, including education for institutionalized individuals with handicapping conditions, and (c) the use of improper and discriminatory classification and placement procedures with this population.

Right to Education and Due Process

The first legal breakthrough (Levin, 1977) for persons with handicapping conditions came in the 1971 PARC decision when a three-judge panel ordered the state of Pennsylvania to identify, within 90 days, every child with mental retardation not in school and to begin teaching them. The decree made these children eligible for regular or special classes from the age of 6 to 21. It also prohibited any school from postponing or denying entry to any child with mental retardation and from altering a child's placement without notifying the parents and giving them an opportunity for a hearing.

Prior to this ruling, children with mental retardation in the state could be excluded from the public schools if a school psychologist determined them to be "uneducable and untrainable" or if they had not attained the mental age of 5.

The following year, the right to education was extended to youngsters with all types of handicapping conditions--not just those with retardation--by the Mills court. In addition, U.S. District Court Judge Joseph C. Waddy rejected the Board of Education's scarcity of funds defense, saying that "available funds must be expended equitably in such a manner that no child is entirely excluded from a publically-supported education consistent with his needs and ability to benefit therefrom." (Mills vs. The Board of Education of the District of Columbia 348 F. Supp. 876 (D.D.C. 1972))

The opinion further specified procedures guaranteeing due process as required by the Constitution and the right to a hearing if parents consider their child's education to be inadequate.

These two decisions blazed a trail for access to education for all children. Logical extensions of this concept are the right to an education suited to the conditions and needs of children with disabilities, the right to free education for children with handicaps since it is provided free to nonhandicapped children, and the right of children with handicaps to be transported to their school programs if necessary (Turnbull, 1975).

Rights of Institutionalized Persons

Substandard conditions, cruel and unusual punishment, and the lack of appropriate programs in institutions for persons with handicapping conditions are other issues which the courts began to address during this period. Court-ordered remedies for these problems affect the design of public policy for persons with disabilities to this day. While not every court agreed on the extent of the states' responsibility for those with handicaps, two decisions, Wyatt, 1972 and Welsch, 1974, held that the state's responsibility is to habilitate those in its care and establish minimum standards by which to judge compliance (Turnbull, 1975). These standards required the hiring of additonal and better qualified-staff; prohibited or restricted certain types of treatment; required the development of individualized treatment plans for residents of the institutions; and established due process procedures in accordance with the 5th and 14th Amendments.

In addition to the concept of procedural fairness, the Wyatt court required the state to demonstrate that a proposed institutional confinement is the least restrictive environment consistent with the needs of the person (Gerry and Benton, 1982).

Nondiscriminatory Evaluation and Due Process

Advocates have argued that denial of appropriate education is tantamount to denying a person an opportunity to acquire property (Turnbull, 1978), and the decision to place a child with a handicap in any setting other than that used for his able-bodied peers is inherently restrictive and, consequently, a deprivation of individual liberty (Abeson, Bolick, Hass, 1975). The Fifth and Fourteenth Amendments guarantee that a person may not be denied liberty or property except by due process of law. Among other things, these Amendments then safeguard persons with handicaps against unfair educational evaluations and placements. In fact, in 1967, the Hobson court ordered a halt to the use of IQ tests for tracking purposes. In Diana (1970 and 1973), the court criticized the manner in which tests were administered and established testing procedures. Retesting in the child's native language was ordered.

Throughout these cases, several principles emerge which were repeated in or which paralleled state and federal legislation for the education of those with handicaps:

- The right to education and treatment for all--regardless of the type of handicap or location where education is delivered;
- The right to fair and periodic evaluation of educational and health-related needs;
- The right to an education individually designed to meet the unique needs of students with handicapping conditions; and
- The right to due process protection of the law.

STATE LAW

State legislatures joined with the nation's judicial system to provide more of the building blocks upon which P.L. 94-142 was based.

Abeson reports that nearly 70 percent of the states had passed mandatory legislation requiring the education of children with handicapping conditions by 1972. Three years later, all but two states had done so. The rise in state mandatory legislation along with the continuing success in litigation testified to an increasing public awareness prior to the passage of P.L. 94-142 (Abeson, 1974).

State legislation, however, did more than provide evidence of a rise in consciousness on the part of public policy makers. In large measure, the federal law modeled actual provisions of state law:

> By 1974, in addition to establishing, through legislation, a handicapped child's right to an education, twelve states had laws requiring due process procedures, and thirteen required the same through their regulations. Six states at that time had legislative language requiring handicapped children to be educated in the least restrictive environment and eleven made that stipulation by regulation (Zettel and Weintraub, 1978, p. 11).

In addition, twenty-two states required, by statute or regulation, "that handicapped children be educated in regular classes for at least some portion of their school day" (Zettel and Weintraub, 1978, p. 11).

The right to education, due process procedures, and education in the least restrictive environment--concepts which formed the framework for The Education for All Handicapped Children Act of 1975 (P.L. 94-142) originated as principles of state policy. The influence of litigation upon the development of state law is apparent by the fact that 37 of the 48 contiguous states had adopted their special education legislation since 1970 (Zettel and Weintraub, 1978).

FEDERAL POLICY

Despite the spectacular activity in the courts and in state legislatures increasing educational opportunities for students with disabilities, hundreds of thousands of them were still excluded from school in 1974 (Children's Defense Fund, 1974). Congressional hearings in 1975 still found ample evidence that equal educational opportunity for children with handicaps was far from a reality:

- Over 1.75 million handicapped children in the United States were still being totally excluded from receiving an education solely on the basis of their handicap.

- Over half of the estimated handicapped population in this country was not receiving the appropriate educational services they needed or were entitled to.

- Many children were still being inappropriately placed in educational settings because their handicaps were undetected or because of a violation of their individual rights.

- Families were forced to find services outside the public education system, often at great distance from their residence and at their own expense (U.S. Congress, Senate, 1975).

The Education for All Handicapped Children Act of 1975

The response of the Congress to these needs was the passage of the Education for All Handicapped Children Act of 1975 - Public Law 94-142. Public Law 94-142 amends Part B of the 1966 Education of the Handicapped Act (EHA). While not the first federal initiative in the area of education for children with disabilities (for a history, see, for example, Appendix B in Ballard, Ramirez, and Weintraub, 1982), P.L. 94-142 stands as landmark legislation for this population. Its provisions combine an array of children's rights derived from litigation and state law with the administrative mechanisms necessary to manage federal funding and compliance requirements.

The U.S. Congress set forth the following purposes of the Act on November 14, 1975:

- To assure that all handicapped children have available to them. . .a free appropriate public education which emphasizes special education and related services designed to meet their unique needs;

- To assure that the rights of handicapped children and their parents or guardians are protected;

- To assist states and localities to provide for the education of all handicapped children; and

- To assist and assure the effectiveness of efforts to educate handicapped children (Congressional Record, November 14, 1975, Section 3(c)).

Five principles constitute the rights aspect of the law: (1) the right to an education, (2) the right to a nondiscriminatory evaluation, (3) the right to be educated in the least restrictive environment, (4) the right to an appropriately-designed educational program, and (5) the right to procedural safeguards (Weintraub and Zettel, 1978). Let us examine these principles in turn.

Right to Education

Public Law 94-142 guarantees the availability of a free appropriate public education to all those with handicapping conditions between the ages of 3 through 21. As defined in the Act:

> The term "handicapped children" means mentally retarded, hard of hearing, deaf, speech impaired, visually handicapped, seriously emotionally disturbed, orthopedically impaired, or other health impaired children, or children with specific learning disabilities, who by reason thereof require special education and related services (20 U.S.C. 1401(1)).

This definition establishes two criteria for eligibility under the Act (Ballard, 1977). To be eligible for services, children must have one or more of the handicapping conditions listed in the Act and require special education and related services as a result. Not all children with disabilities require special education. Hence, not all children with disabilities are "handicapped" for purposes of P.L. 94-142.

"Special education" is defined in the Act as:

> . . .specially designed instruction, at no cost to parents or guardians, to meet the unique needs of a handicapped child, including classroom instruction, instruction in physical education, home instruction, and instruction in hospitals and institutions (20 U.S.C. 1401(16)).

Of particular importance to health professionals is the section of the Act which defines "related services" to mean:

> . . .transportation, and such developmental, corrective, and other supportive services (including speech pathology and audiology, psychological services, physical and occupational therapy, recreation, and medical and counseling services, except that such medical services shall be for diagnostic and evaluation purposes only) as may be required to assist a handicapped child to benefit from special education, and includes the early identification and assessment of handicapping conditions in children (20 U.S.C. 1401(17)).

Taken together, these two definitions set forth what must be provided to handicapped children to guarantee their right to an education, namely, specially designed instruction to meet the unique educational needs resulting from their handicapping conditions, and additional related services to the extent necessary for the child to benefit from special education.

Nondiscriminatory Evaluation

As discussed earlier, a disproportionate number of minority children classified as retarded or slow learners raised questions about the mislabeling of students in several court cases prior to P.L. 94-142. To address this issue, Congress enacted three evaluation provisions as part of the Act. First, testing and evaluation materials and procedures used in placing children with handicapping conditions must not be racially or culturally discriminatory. Second, assessments must be conducted in the child's native language or mode of communication (sign language is an example of the latter). Third, no single procedure shall be the sole criterion for determining an appropriate educational program for the child (20 U.S.C. 1412 5(c)).

Alfred Binet's concern about labeling and resulting stigmatization is the more dramatic originating as it does from the developer of one of the first intelligence tests at the turn of the century: "It will never be to one's credit to have attended a special school. We should at the least spare from this mark those who do not deserve it" (Binet in Abeson, Bolisk and Hass, 1975, p. 25). The re-evaluation provisions in federal policy for the education of children with disabilities seek to prevent mislabeling while ensuring the availability of diagnostic data upon which to base educational decisions.

Least Restrictive Environment

Expanding upon the Wyatt decision and state policy, Congress required that:

> . . .to the maximum extent appropriate, handicapped children, including children in public or private institutions or other care facilities, are educated with children who are not handicapped, and that special classes, separate schooling, or other removal of handicapped children from the regular educational environment occurs only when the nature or severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily (20 U.S.C. 1412 5(B)).

As Weintraub and Zettel (1978) emphasize, this does not mean that all children with handicapping conditions will or should be placed in a regular education classroom. Rather, the intent is to ensure that a variety of options or program settings exist to be used according to the individual needs of each child. The strength of the language of this provision reflects the grave consequences of denying individuals their right to liberty or property or both by unnecessarily removing or depriving them of a regular education program.

Individualized Education Program (IEP)

The right to an individually-designed educational program (IEP) derives from the requirement that the education of youngsters with handicaps be appropriate to their needs. Deprived of this safeguard, education for such children would be a hollow promise. One need only imagine a child who cannot read without the aid of brailled texts, a child unable to hear the teacher's instruction, or a child with mental retardation failing in the chemistry class in which he/she was placed to see the need for a provision such as the IEP.

An IEP is the mechanism used by Congress to ensure the appropriateness of the special education and related services delivered to children with handicaps. Simply put, an IEP is a statement of what will actually be provided to the child. It must be collaboratively developed at a meeting consisting of an authorized representative of the local education agency, the teacher, the parents or guardians of the child and the child whenever appropriate, and it must be annually reviewed and revised if necessary. Federal law specifies that an IEP must include:

(A) a statement of the present levels of educational performance,

(B) a statement of annual goals, including short-term instructional objectives,

(C) a statement of the specific educational services to be provided to such child, and the extent to which such child will be able to participate in regular educational programs,

(D) the projected date for initiation and anticipated duration of such services, and

(E) appropriate objective criteria and evaluation procedures and schedules for determining, on at least an annual basis, whether instructional objectives are being achieved (20 U.S.C. 1401(19)).

Similar provisions occur in other federal programs such as the Social Security Act and Vocational Rehabilitation. The IEP, like the Individualized Written Rehabilitation Plan (IWRP) used in vocational rehabilitation, is a management tool. It does not require children to be individually taught, or promote any particular curriculum or methodology. The IEP sets forth both what an appropriate education is and the least restrictive environment in which it is delivered.

Procedural Safeguards

P.L. 94-142 provides guarantees of fairness in educational decision-making through a series of interlocking procedures. These procedures mirror those of the right to education cases previously discussed. Included are: access to school records; the right to independent evaluations; surrogate parents or other means of representation if a child's parents are unknown or unavailable or he/she is a ward of the state; prior notice before a school proposes or refuses to initiate or change the child's identification, evaluation, placement, or provision of a free appropriate public education; an opportunity for a hearing before an impartial hearing officer; and the right to be assisted by counsel and expert witnesses at the hearing. Other hearing rights include the right to present evidence, cross-examine witnesses, subpoena witnesses, present oral or written arguments, receive a copy of the officer's decision, and appeal to the state educational agency.

Due process applies to schools as well as to parents. Either party may request a hearing. This two-way process provides the maximum opportunity for decisions to be made in the best interests of children with handicapping conditions.

Funding

The third purpose of P.L. 94-142--to assist states for the education of children with handicaps--is accomplished through grants to states participating in this federal program*.

From an appropriations standpoint, P.L. 94-142 is the fastest-growing federal education program. In total dollars, the Act ranks only behind Chapter I of the Education Consolidation and Improvement Act (for disadvantaged students) and the combined appropriation for all higher education student assistance programs (Insight September, 1979).

This apparently rosy picture is marred by the fact that current appropriations are substantially below the authorization levels which Congress originally approved. In 1975 when the law was passed, the federal share of the education of children with handicapping conditions was to gradually escalate until it reached a maximum of 40% in

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*New Mexico is the only state choosing not to participate under this Act. Under a January 8, 1980 court ruling, New Mexico Association for Retarded Children, et. al. vs. the State of New Mexico, et. al., the state is required to provide substantially the same services as required by P.L. 94-142 under Section 504 provisions. The growth in appropriations for P.L. 94-142 and the prior EHA Part B has increased from $50 million in fiscal 1973 to $931 million in fiscal 1982.

1982. (This percentage is based on the national average expenditure per public school child times the number of children with handicaps being served.) In the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-12), Congress has capped the original fiscal formula for a three year period to put a ceiling on appropriations through 1984. In fiscal 1982, the Public Law 94-142 grant program contributed about $233 per child, amounting to a federal share of under 9% of the national average per pupil expenditure.**

P.L. 94-142 and Section 504

Any discussion of the education and related health rights of children with disabilities must include Section 504 of the Rehabilitation Act of 1973, as amended, since compliance with this Act is also required. This civil rights legislation consists of one sentence:

> No otherwise qualified handicapped individual in the United States as defined by Section 7(6) shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefit of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.

Effective since 1977, the Act received its interpretation in the regulations promulgated by over 30 federal agencies. Applied to education, Section 504 closely parallels P.L. 94-142 in that it guarantees a free appropriate public education to students with handicapping conditions and includes provisions for individualized education programming, education in the least restrictive environment, nondiscriminatory assessment, and procedural safeguards.

In addition to education, Section 504 pertains to employment, and program accessibility in hospitals, colleges and universities, nursing homes, daycare centers, welfare offices, and other recipients of federal financial assistance. Because of its broad applicability, Section 504 has had a profound impact on the struggle of persons with disabilities to obtain equal access to education, health, and social service institutions. Notable differences, however, exist between the P.L. 94-142 and Section 504 definitions of handicap, ages covered, funding and enforcement.

**Figures are based on FY 82 handicapped child count of 3,990,415 and an estimated national average per pupil expenditure of $2,700 for that year using National Center for Education Statistics data.

The Section 504 definition of who is handicapped goes beyond the P.L. 94-142 categories. The Section 504 regulations identify a "handicapped" person as anyone with any type of physical or mental disability that substantially impairs or restricts one or more major life activities, such as walking, seeing, hearing, speaking, working, or learning. Handicapping conditions include but are not limited to:

- Cancer
- Cerebral palsy
- Deafness or hearing impairment
- Diabetes
- Emotional illness
- Epilepsy
- Heart disease
- Multiple sclerosis
- Muscular dystrophy
- Orthopedic, speech or visual impairment
- Such perceptual handicaps as:
  - --Dyslexia
  - --Minimal brain dysfunction
  - --Developmental aphasia
- Mental retardation

The U.S. Attorney General has ruled that alcoholism and drug addiction are physical or mental impairments that are handicapping conditions if they limit one or more of life's major activities.

P.L. 94-142 applies to persons with handicapping conditions through the age of 21, while there is no age limit under Section 504. P.L. 94-142 operates as a state grant program; no funds are authorized under Section 504. The Office of Special Education and Rehabilitation Services of the U.S. Department of Education administers P.L. 94-142. The Justice Department is the lead agency for administering Section 504. Enforcement in education is carried out through the U.S. Department of Education's Office for Civil Rights.

Summary of Federal Law

Taken together, Public Law 94-142 and Section 504 guarantee the following rights and protections to America's children who are "handicapped" under the law:

- A free appropriate public education for all children and youth requiring special education and related services;

- Comprehensive nondiscriminatory assessment procedures;

- Individualized education programs (IEPs) including parental involvement in planning and decision making;

- Education in the least restrictive environment (LRE), that is, education with nonhandicapped children to the maximum extent appropriate; and

- Procedural safeguards including due process for parents and children.

DIFFERENCES BETWEEN FEDERAL AND STATE LAW

Many differences between federal and state law for educating children with disabilities were eliminated in the first year of implementating P.L. 94-142 (1977-78) yet differences still exist. Allied health professionals interested in understanding the policy in their own state should contact their member of the legislature for a copy of the state law and the state or local director of special education for current state regulations. The following lists likely areas of differences not only between federal and state requirements but also among the states themselves:

- **Ages of Eligibility** - Depending on the state and handicapping condition, children may begin school at birth, age 3, 4, 5 or 6. Education may stop at graduation, age 18 or continue until or through age 21 (Barresi and Mack, 1980).

- **Eligibility Criteria** - Differences in test cut-off scores and other eligibility requirements may make a child eligible for special education and related services in one state but not in another.

- **IEP Requirements** - IEP contents and required participants in most states exceed those federally required (Mack, 1980).

- **Due Process** - Some states have added formal and informal mediation steps to the process prior to a hearing; others have eliminated the local hearing and only hold one state level due process hearing (U.S. Department of Education, 1982).

- **Length of the School Year** - As a result of litigation, some states now provide special education and related services over the summer months to some children with handicaps. Others make schedule adjustments for children of migrant workers.

- **Administrative Arrangements** - Varying agency responsibilities and demographic circumstances mean that allied health professionals may work in numerous agencies other than the education agency and still provide related services to children with disabilities on a contract basis as part of an interagency agreement, cooperative arrangement or other administrative settlement.

- **Professional Credentials** - Differences in state certification and licensure, agency requirements, and the lack of nationwide reciprocity means that allied health professionals must verify their employability in each state and even, in each agency.

FUTURE OUTLOOK

Eight years after its enactment, P.L. 94-142 has successfully withstood attempts to repeal it completely, fold it into a block grant to remove its categorical mission, drastically reduce its appropriations, gut its regulations, and undermine its enforcement.

A battlecry of the "new federalism" philosophy - getting the federal government out of education on the grounds that the Constitution gives states this responsibility - failed to rally sufficient support for this goal. The public responded negatively to such attempts and Congress was persuaded. Advocates also could have responded with a legal argument using the Fourteenth Amendment. The Constitution charges the federal government to ensure equal protection of the law to all inhabitants of the United States. This equalizing function is why federal aid to education has been mostly categorical in nature with financial assistance targeted to specific needs. Though not proposed on such grounds, P.L. 94-142 effectively operates to ensure youngsters with handicaps equal access to education.

Deregulation as a solution to the nation's pervasive economic crisis was shown to be a suspect, if not a bankrupt, solution when applied to P.L. 94-142.

> Reregulation is the essence of the proposed rules, not deregulation. State and local agencies would be obliged to spend several years and untold personnel hours and dollars gearing up to new regulations, just when they have achieved fairly widespread compliance with present regulations. They would have to retool all procedures and standards relating to monitoring, site and paper compliance, technical assistance, policy interpretations, and inservice and preservice training. The result inevitably will be dilution of effort from present (and long overdue) attention to quality education and redirection of fiscal resources from one compliance standard to a new one (Turnbull, 1982).

Changes in the regulations proposed by the Reagan Administration on August 4, 1982 were almost universally rejected by state and local governments, school personnel, parents and advocates of children with handicaps and were subsequently withdrawn. Testimony from days of hearings held around the country on the proposals is being analyzed as this article goes to press. Since these proposals were negatively received, they probably will not be revised. Advocates expect the 1977 original final regulations, with minor modifications, to prevail for some time.

P.L. 94-142 is not without its share of detractors. Local responsibility and private initiative arguments are heard from supply-side economists. Yet attempts to fold P.L. 94-142 and other programs of the Education of the Handicapped Act into a block grant in order to release states from having to use these funds solely for students with handicapping conditions have failed and no further attempts are anticipated.

Support for the purposes of P.L. 94-142 is widespread and bipartisan. The future of federal assistance for the education of youngsters with handicapping conditions looks promising.

Courts In The Future

The right to education movement discussed earlier blazed a new trail in the struggle for equality by citizens with handicaps, their parents, and their advocates. Now that this right is protected as a matter of federal policy through P.L. 94-142 and Section 504, courts are largely interpreting, clarifying or expanding the basic rights and provisions of these laws and corresponding state mandates, rather than breaking new ground (Smith and Barresi, 1982).

Recent state and federal courts have ruled in Section 504 disputes concerning the definition of "otherwise qualified" handicapped persons (Davis vs. Southeastern Community College), an individual's private right of action (Camenish vs. University of Texas), and the need for individuals seeking judicial relief to first exhaust administrative remedies (Larry P. vs. Riles).

Other examples of litigation expanded the right to education by awarding compensatory services to persons with handicapping conditions denied an appropriate education in the past (Mattie T. vs. Holladay), protecting students with handicaps from unfair suspensions and expulsions (S-1 vs. Turlington), providing bilingual special education for students with handicaps whose primary language is other than English (Dyrcia S. et. al. vs. Board of Education for the City of New York), requiring schooling beyond the normal school year for children with handicaps who are unable or unlikely to recoup skills lost over summer breaks (Armstrong vs. Kline), and the right of youth with handicapping conditions held in juvenile corrections facilities or child welfare agencies to receive an appropriate education (Willie M.,et. al. vs. James B. Hunt, et. al.).

Turnbull (1978) suggests five future areas of litigation:

- **Zero reject.** Claims for early intervention, greater participation in programs such as vocational education, school health, counseling, job-hunting and extracurricular activities, and the effect of minimum competency testing laws on handicapped students are likely issues.
- **Nondiscriminatory evaluation.** Tests themselves and the uses to which they are put may come under legal scrutiny along with placement decisions based heavily upon teacher recommendations and adaptive behavior assessment.
- **Appropriate education.** The quality of special education programs compared with that of regular education in terms of numbers and qualifications of staff and availability and appropriateness of materials are ripe areas under the equivalency standards of Section 504.
- **Least restrictive environment.** The relative richness or poverty of educational services in separate programs as a factor in determining the least restrictive environment appropriate to the students' needs is a likely future issue along with community-based services.
- **Procedural due process.** School initiated, rather than parent-initiated, due process hearings could become a future trend.

IMPLICATIONS FOR ALLIED HEALTH

The provision of special education and related services to meet the unique needs of children with handicaps means that the professionals delivering these services have intertwining responsibilities. New relationships between education and social service and other community agencies have been formed. Interpretations of what constitutes related services, who provides them, and how they are to be delivered and coordinated, have expanded the roles of professionals beyond their traditional definitions.

Allied health professionals are called upon to conduct evaluations, attend IEP meetings, follow procedural safeguards and deliver related services to handicapped children under P.L. 94-142 and Section 504. Professional accountability requires continuous professional development, refinement of skills, and a highly developed sensitivity.

Appendix 1A contains selected portions of the P.L. 94-142 regulations and discusses their implications for health professionals. Understanding these provisions is critical to effective coordination and advocacy on behalf of individuals with disabilities and their families.

To be fully informed, however, health professionals need to know state as well as federal policy. State policy--including statute, regulation, attorney general opinions, court orders, and official policy-setting memoranda--changes more frequently than federal policy. Health professionals should contact their state director of special education, listed in Appendix 1B, for a copy of their state guidelines. Further suggestions for obtaining current information are discussed in **Unit 6** in a useful section entitled "Resources for Effective Advocacy."

CONCLUDING REMARKS

Public Law 94-142 and Section 504 are turning points in the struggle for full citizenship rights for persons with disabilities. Yet, public policy, though necessary and persuasive, is insufficient to produce the widespread, positive attitudinal changes that alone result in total acceptance and equality for persons with handicapping conditions.

Zigler (1972) states that we treat so many of our social action programs as fads: we love them too much when they are young, and we despise them too much when they become older. Health professionals must not be content with knowing that our education and health service systems are better today than they have ever been; rather we must ask whether they are good enough for the people we serve.

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A Primer on Individualized Education Programs for Exceptional Children: Preferred Strategies and Practices. 2nd Edition. 1978. Daniel P. Morgan. 1981. The Council for Exceptional Children. 128 pp. Price $7.50, members $6.38.

Clarifies problems, questions, misconceptions about IEP issues. Includes suggestions regarding assessment, communication between professionals, delivery services and the parents' role.

Exceptional Timetable: Historic Events Affecting the Handicapped and Gifted by Jean Nazzaro. 1977. The Council for Exceptional Children. 55 pp. Price $5.75, members $4.89.

A companion to the film Exceptional Times but may also be used alone. Charts major events in the development of special education in the United States from 1800. Events are categorized as follows: climate of the times; advocacy and litigation; technology, service, health, and innovation; programs, state policy; and federal policy.

Public Law 94-142 and Section 504 - Understanding What They Are and Are Not. 1980. The Council for Exceptional Children. 15 pp. Price $1.50, members $1.35.

Clear and concise description of each law.

Public Policy and Educating Handicapped Persons. Edited by Maynard C. Reynolds and John Brandl. 1983. The Council for Exceptional Children. Approximately 250 pp. Price $10.00, members $8.50.

Examines the emerging system(s) of educating handicapped children, program effectiveness, public education, coordination with other service systems, costs of experimentation, restructuring "special" school programs and social policy.

Section 504 of the Rehabilitation Act of 1973 Fact Sheet: Handicapped Persons Rights under Federal Law. March 1978. U.S. Department of Education, Office for Civil Rights. 10 pp., pamphlet. Free.

Exceptionally good brief summary to hand to anyone seeking general information on Section 504.

Section 504: Self-Evaluation Guide: Preschool, Elementary, Secondary, and Adult Education. Civil Rights-Handicapped Persons and Education. August 1978. U.S. Department of Education, Office for Civil Rights. 116 pp. Free.
A self-evaluation guide for colleges and universities is available at the same address.

Special Education in America: Its Legal and Governmental Foundations. Edited by Joseph Ballard, Bruce Ramirez, and Frederick J. Weintraub. 1982. The Council for Exceptional Children. 112 pp. Price $22.50, members $19.13.

Provides a clear, compelling history and status of legislation and litigation affecting the education of handicapped ad gifted children to date.

The Rehabilitation Act: An Analysis of the Section 504 Regulations and Its Implications for State and Local Educational Agencies. 1977. National Association of State Directors of Special Education, Inc. 12 pp., paperback. Price $2.50.

Excellent summary of Section 504.

The Rights of Handicapped Students by Christiane H. Citron. 1982. Education Commission of the States. 124 pp. Price $6.00.

Provides comprehensive and detailed information about the education-related rights of handicapped children. Based on an analysis of state and federal statutes, constitutional underpinnings, and judicial interpretation. State special education statutes are listed and analyzed in tabular form.

SPECIAL NOTES

To obtain a copy of P.L. 94-142, write to your member of the U.S. House of Representatives, or to one of your U.S. Senators.

To obtain a copy of the final regulations for P.L. 94-142, get a copy of the Federal Register for Tuesday, August 23, 1977 from the Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402. Price $1.50.

To obtain a copy of the final regulations for Section 504 of P.L. 93-112, get a copy of the Federal Register for Wednesday, May 4, 1977.

Because an experience of having a handicap oneself can help overcome barriers of fear and ignorance, lead to a positive viewpoint, and increase one's sensitivity toward persons with handicaps, the following manual containing 25 activities which simulate handicapping conditions is recommended:

Everybody Counts! A Workshop Manual to Increase Awareness of Handicapped People, by Michael J. Ward, Robert N. Arkell, Harry G. Dahl and James H. Wise. (Available from the Council for Exceptional Children, 1920, Association Drive, Reston, VA. 22091. Price $14.95, members $12.71.)

UNIT 2

Roles and Responsibilities

ANTHONY S. BASHIR

UNIT 2: ROLES AND RESPONSIBILITIES

PURPOSE AND OBJECTIVES

Purpose:

To explore the roles and responsibilities of health professionals in identifying, referring, and advocating on behalf of children and youth with disabilities.

Specific Objectives:

At the conclusion of this unit, readers should be able to:

1. Discuss the impact of Public Law 94-142 on the roles and responsibilities of all health professionals.

2. Identify the barriers to effective service delivery and the responsibilities of health and education professionals in developing solutions.

3. Describe the roles and responsibilities of individuals in the related-health professions with respect to the needs and rights of children and youth with disabilities, including:

    a. providing effective and competent services;
    b. using effective communication strategies;
    c. identifying, referring, and advocating for youngsters with disabilities and their families;
    d. understanding relevant local, state, and federal laws, regulations, and procedures; and
    e. cooperating and coordinating with other professionals in the delivery of health and education services.

UNIT 2

Providing Services to Youngsters With Special Needs: Roles and Responsibilities of Health Professionals

ANTHONY S. BASHIR

An understanding of the nature of handicapping conditions and the needs of individuals with these conditions has changed over the past ten years. In part, the changes have resulted from insights gained from clinical and research endeavors that clarified the nature of handicapping conditions, the needs of individuals with these conditions, and the long-term consequences of disabilities. Further, as identified in the preceeding unit, the passage of Public Law 94-142 and the Rehabilitation Act of 1973 has ensured individuals with handicapping conditions appropriate educational and vocational services, mandating additional changes in the character and procedures of practice for both the education and related-service professions.

Improvement in methods of preventing catastrophic outcomes, the advent of early identification and treatment programs, changes in the delivery of educational and rehabilitation services, and increased cooperation among health and education professionals in assessment, planning, and intervention also have contributed to changes in care. These changes affect not only the youngsters and their care providers, but their families, friends, and classmates as well.

The vast majority of children and young adults with handicapping conditions are assessed and receive services through their public school systems; others receive services in such diverse settings as medical-clinical facilities, early intervention or high-risk programs, and Head Start programs. Without question, there have been significant improvements in the ways in which individuals with disabilities are served. Still, there are individuals who are not involved in programs appropriate to their needs, receiving little or no education, inappropriate services, duplicate services, or services that functionally are not coordinated.

To address the changing service-delivery demands in health care and education, professionals serving youngsters with special needs must "recognize and accept the responsibility to **advocate** for the **entire** child"; that is, to promote and facilitate full, total care adapted to the life-long needs of the youngster (Del Polito, 1983, p. 3). Appropriate, total care for youngsters with handicapping conditions can be realized only when professionals in the health care and human service systems join with those in education to form new alliances for providing quality services and accepting responsibility for identifying and referring these individuals--and for advocating on their behalf.

To assist professionals in health and education in examining their responsibilities for these youngsters, this unit will examine the barriers to the delivery of effective services, and the professional and personal skills required to meet the needs of youngsters with handicapping conditions and their families.

BARRIERS TO THE DELIVERY OF SERVICES

If improvements in assessment and management of youngsters with handicapping conditions are to occur, health professionals must engage in a careful consideration of the barriers that interfere with effective service delivery. In the **Introduction**, a number of barriers to effective provision of services in health and education were discussed. They included the effects of labels, the restrictions imposed by attitudes toward individuals with handicapping conditions, the lack of coordination and advocacy on behalf of individuals with handicapping conditions, and the concerns associated with the ethical and moral aspects of service delivery.

Based on their extensive experiences as care providers, health and education professionals, participating in The American Society of Allied Health Professions' (ASAHP) regional conferences, identified problems that affect the roles and responsibilities all health professionals need to assume to provide effective programs for individuals with handicapping conditions and their families.

Among the many barriers and problems identified by leaders in health and education across the country are issues associated with:

- Legal and regulatory processes;
- Societal, cultural, and professional attitudes;
- Professional practice issues, including scope and limits of practice, content knowledge, and ethical responsibilities;
- Communication effectiveness in interpersonal and interprofessional situations with colleagues, as

well as in the delivery of services to individuals and their families; and

- Programmatic options and continuity of care.

Some of these barriers--and the issues associated with them--are discussed in detail in other parts of this publication. This overview describes the issues and provides a stimulus for further study and discussion.

Legal and Regulatory Issues

A clear understanding of the rights provided for individuals with handicaps is fundamental to effective service and advocacy. Too often, health professionals have only cursory or hearsay information about the laws, their regulations, and those individuals for whom the legislation is intended. Health professionals must know what conditions qualify as "handicapping" under Public Law 94-142 and Section 504 of the Rehabilitation Act. Only then can they appropriately advise and refer clients and their families. Misinforming individuals and families about their rights and education options can lead only to confusion, mistrust, and interprofessional conflict.

In addition to knowledge about the legislation which affects children and young adults with handicapping conditions, health professionals need to understand the regulations which have been designed to implement the law. Attention to the requirements for multidisciplinary team evaluations, inclusion of appropriate and qualified professionals in evaluations, use and number of relevant tests administered, and the language in which the evaluations are conducted are only a few of the regulatory policies that must be accommodated. When regulatory processes are breeched, additional legal barriers surface.

Further, health professionals need to recognize the critical differences which exist between federal, state, and local requirements for assessment procedures and service delivery. These differences may create barriers by altering the definitions of handicapping conditions; the type and composition of evaluation teams; the use of appropriate and qualified professionals; the processes for requesting second opinions; as well as limiting the role of the family members. A study of the unique aspects of one's state's laws is critical to planning appropriate implementation strategies for youngsters in the state.

Societal and Professional Attitudes

Barriers associated with societal and professional attitudes are addressed more extensively in other sections of this text (see the **Introduction** and **Unit 3, Communication**). Attitudinal barriers have their basis in many sources, including generalizations made about the term "handicapped" and the often-resulting telescopic view of individuals with handicaps. Another source is a lack of appreciation for the unique socio-cultural beliefs and parenting practices of individuals from different ethnic traditions or racial backgrounds. Attitudinal barriers also result from denial by both parents and professionals. Failure of the family to admit to the condition of the child because of fears associated with socio-cultural criticism or judgement, as well as failure of professionals to admit to treatment ineffectiveness, to their fears of losing a client and family to another care provider, or to their distorted perceptions of the scope and limits truly imposed by professional training are only a few additional sources of attitudinal barriers.

Professional Practice and Training

Health professionals, through their own practices and by their own regard for each other, are responsible for creating many of the barriers to effective service delivery. In addition to the lack of coordination in case management, addressed in the **Introduction**, these barriers include, among others:

- Unresolved differences in philosophy of care;
- Competition for limited financial resources;
- Professional turf arguments;
- Confusion and mistrust among professionals with regard to their respective roles and responsibilities for service delivery; and
- Ineffective programs of continuing education.

Varied **philosophical positions** and the vested interests of some health professionals have resulted in significant differences in perspectives about roles and responsibilities for individuals with special needs. These differences are not always in the best interests of youngsters with handicaps or their families. In some instances, these differences are maintained as a kind of professional arrogance. When professionals make the client the battleground on which to work out these differences in perspective, no one profits. Some members of the team may be reduced to token positions, while others may be elevated unjustifiably to primacy roles in the decision-making process. Professional arguments potentially result in distortion, leaving the client and family confused with splintered and uncoordinated services.

Professional parochialism also is fostered by diminishing financial resources and the **competition** for funds. This issue affects both training efforts and employment security. Who will receive the money that is available? Who will deliver the services to this child? Whose training has better prepared them for dealing with the needs of this individual with a handicap? These are questions that merit careful consideration. They are not questions, however, which should be asked or answered in the hope of establishing a self-justified territory of practice.

Appropriate resolution of these concerns will depend upon a clear knowledge of the needs of persons with different handicapping conditions and the distinct contributions different health and education professionals make to the care of individuals with handicaps. Mutual professional respect is essential. In addition, new cooperation within institutions of higher education at the interdepartmental and intercollegial level needs to occur. Examination of educational policies, curricula, and practicum designs, stressing both interdisciplinary core studies and the unique disciplinary issues of professional preparation, need to be addressed.

In discussions across the country, leaders in health and education noted other barriers which exist because of ineffective methods for providing **continuing education** opportunities. Inservice programs are the principal means by which agencies (health and education) facilitate changes in the interactions between care providers and individuals with disabilities. Among the deterrents to effective inservice programs are:

- Lack of appropriate prior planning and organization of goals and content;
- Inappropriate use of personnel in faculty roles;
- Irrelevant presentation of information; and
- Limitation of participation on the basis of professional role.

Since inservice programs are necessary to accommodate differences in preservice training as well as to provide a means for continued professional growth, it is essential to overcome these barriers. Solutions to these problems will begin when program designs are based on prior needs assessments which consider the needs of individuals with disabilities and their families, as well as the needs of the diverse groups of professionals who provide services.

As appropriate, individuals with disabilities and their families should be involved in planning instructional programs. The unique needs of the local community and the health/educational setting must be considered, with faculty selected on the basis of qualifications to address program content. Wherever possible, the design and implementation of programs should be multidisciplinary: participants should not be separated on the basis of their professional roles. Further, the success and continued existence of programs will depend upon the clear and consistent support of administrators. Specific recommendations for professional training programs are provided in the **Instructors Guide** which accompanies this text.

Communication Effectiveness

The individual with a handicapping condition and his/her family bring a series of concerns to the health professional. In turn, the health professional is responsible for acknowledging these concerns and addressing them within the scope and limits of their training. Often, the health professional's busy schedule, lack of desire to become involved, lack of ability to know how to address issues not related directly to their practice, or fear of being perceived as "not knowing," will lead the professional to dismiss or ignore aspects of the individual's or family's concerns. This poses barriers to practice and service which, when not resolved, potentially jeopardizes the individual and family as well as their relationship with the health professional.

Too, the inappropriate exclusion of individuals and their families from active participation in decision-making may undermine the efforts of health professionals, in spite of the competencies of professionals or the provision of adequate programs. As appropriate and feasible, clients and families should work in cooperation with professionals at all levels of planning, including the design of treatment and educational programs for the client, the development of professional training programs, and the formulation of laws and regulations.

As integral members of the multidisciplinary team, health professionals also may encounter barriers associated with the dynamics of group membership. In the multidisciplinary team, the "politics" of care are aired and resolved, hopefully to the benefit of the client and family. True, shared decision-making on the part of team members is possible only when the insights, examination results, histories, and differences in opinion are resolved in the formulation of a diagnosis and in a prioritization of needs for the client and family.

Planning, design, and implementation of services begin with all team members' clear understanding of what constitutes a disability. Professionals from different backgrounds may have varying perceptions about an individual's attending behaviors, cooperation, or ability to relate. In addition, each professional will contribute unique analyses based on the results of specific test batteries and will provide pertinent information germain to the individual's history, past therapies and therapeutic experiences, educational experiences, as well as professional concerns for and of the family.

It is the **integration** of material from multiple sources and perspectives that will clarify the pattern of strengths and weaknesses demonstrated by the individual suspected of having a handicapping condition, identify how the disability will constrain the individual physically, intellectually, and emotionally, and lead to the process of shared decision-making to establish the priorities for the individual's educational and treatment programs.

In formulating a disposition, those health professionals practicing in clinical or medical centers will need to develop strategies for the orderly transfer of care to appropriate educational or other service agencies. Communication barriers with the family will need to be addressed and assurances given to the family on the roles team members will continue to play both with the family and with the referral agency. Follow-up mechanisms need to be formulated and clearly delineated for the family. The advocacy role is clear.

Solutions to communication barriers can begin with an examination of the scope and limits of practice, the development of effective listening and problem-solving strategies to assist the client and family in appropriately stating their concerns, and in the development of effective referral mechanisms to involve qualified individuals or community and state resource agencies. Assisting families and individuals to make transitions from one care team to another will be as important as providing direct care. Providing direct care is only one responsibility of the health professional. Facilitating the individual's growth and adaptation through effective strategies of communication and referral are also significant responsibilities for the professional concerned with providing effective services. Appropriate communication and referral strategies are discussed at length in **Units** 3 and 5 respectively.

Programmatic Options and Continuity of Care

Health professionals also have a responsibility to advocate for and participate in the development of a **continuum of service models.** In addition to direct care, there are consulting models, shared-treatment models, and models emphasizing direct participation in the educational process. Whatever model is employed, however, treatment must be coordinated carefully with other aspects of the individual's educational program. When professionals do not act in concert, delivery of services becomes fragmented and results in treatments that address isolated aspects of a person's needs. As appropriate, health professionals must define their roles in terms of their respective services and become integral parts of the care team--not adjunct or parallel systems of care to other educational efforts.

In addition, health professionals will need to overcome those barriers that result from short-term contacts with clients and families and participate actively in the design of a continuum of services. Throughout their lives, individuals with disabilities are at needless risk for failure. Geographical distances between clients and their providers as well as family relocations (e.g., job transfers, migrant working conditions) may restrict continuity of services. Similarly, advocacy efforts among different agencies serving the same individual and family, as well as administrative constraints and costs, may operate as barriers to the development of an appropriate continuum of care. Further, lack of service options or accommodations for adaptive learning or independent living can create substantial barriers for the person with a disability.

Innovative design models and creative fiscal resource allocations can provide program options for all those in need of services and should be the concern of all those responsible for providing health care and education to individuals with disabilities. Different classroom and adaptive curriculum models, prevocational and vocational programs, and programs for facilitating the development of independent living are only a few considerations health professionals will need to address and advocate for at local, state, and federal levels.

Both the immediate and future needs of individuals must be reflected in the plans for intervention, treatment, and educational programming. The required services and program options will be determined by the degree and type of disability, changing patterns and needs made obvious as development proceeds, and the changing demands of the the contexts in which the individual functions. Consequently, review systems must be developed to monitor changes in the individual's status as well as to design services and programs appropriate for the youngster's continued growth and development.

The prudent and coordinated use of local and state resources, as well as collaboration with university training programs can be explored as a means for facilitating services, enhancing cooperation, and promoting professional training and growth. Again, clear commitments are needed from all involved--administrators, professionals, and families alike. With careful study of multiple service-delivery sources and advocacy efforts, improved coordination and continuity of care can result, including interagency communication, systematic development of care networks, reduction of costs, and a variety of program and service options.

ROLES AND RESPONSIBILITES

To address the many barriers to the delivery of education and related health services to youngsters with disabilities, experienced health and education professionals participating in regional workshops around the country identified specific roles and responsibilities all health professionals should assume, whether or not they interact directly or consistently with individuals who have disabling conditions. The roles and responsibilities reported below emerged repeatedly across all regions.* While this list may appear extensive, the roles and responsibilities are not unlike the competencies needed for serving any client. The emphasis and implementation of these roles and responsibilties will vary from time to time, determined primarily by the context of one's professional practice, personal motivation, and environmental and organizational constraints.

Clearly, the competencies suggested by this list are important for all health and education professionals and should not be perceived as limited to those professions which treat children and youth for their handicapping conditions. As indicated earlier, as professionals in the health-care or educational systems, all health professionals will be expected to possess such competence and, therefore, need to be prepared.

1. Roles and Responsibilities Related to Legal and Regulatory Issues

- To understand State and Federal legislation in order to assist families in solving problems related to the child/youth's condition; that is:
    1. To facilitate the provision of appropriate services for the youngster with a handicapping condition;
    2. To facilate parents' understanding of case management procedures for the child/youth;
    3. To facilitate identification of an appropriate case manager for the youngster;
    4. To recognize and provide accurate information to parents;
    5. To assist parents in understanding their legal rights;
    6. To assist parents in defining and accepting their roles and rights; and
    7. To promote self-advocacy skills among youngsters and parents.

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*The individuals participating in the workshops conducted in California, Minnesota, Maryland, Vermont, Tennessee and Colorado represented the professions of Audiology/Speech-Language Pathology, Corrective Therapy, Dental Assistance and Dental Hygiene, Dietetics, Health Education and Administration, Medical Assistance, Medical Technology, Medical Record Administration, Rehabilitation Counseling, Social Work, Nutrition, Occupational Therapy, Physical Therapy, Nursing, Physician Assistance, Psychology, and Recreational Therapy.

2. **Roles and Responsibilities Related to Societal and Professional Attitudes**

   - To recognize and accept the needs and rights of disabled youngsters.

   - To recognize the need to be sensitive to and understand the influence of cultural differences in the identification, referral, and treatment processes.

   - To recognize the prevalent forms of prejudice, stereotyping, and tokenism, and understand how myths and stereotypes contribute to the devaluation of people with disabling conditions.

3. **Roles and Responsibilities Related to Professional Practice--General**

- To provide effective and competent services for which one is trained; that is:

   1. To recognize the indicators of handicapping conditions for severe, mild-moderate, and high-risk children and youth;

   2. To provide appropriate screening programs so as to identify children and youth with possible disabilities and make appropriate referral for assessments;

   3. To provide appropriate assessments of individuals with disabilities; and

   4. To participate in the planning, design, and implementation of programs for individuals with disabilities as appropriate to one's professional concern and practice.

- To understand, implement, and promote methods for identifying appropriate referral sources.

- To maintain accurate records of assessments, treatments, and progress.

- To maintain the use current technologies to share information about clients and their conditions (e.g., computer networks).

- To understand the effects of current treatments on the future performance of the client and to communicate this understanding to parents and clients.

- To educate one's self, parents, colleagues, employers, and communities about the needs and rights of individuals with disabilities and their families and the roles the various professionals perform in providing services.

- To disseminate accurate information to the public concerning:

  1. the nature of disabling conditions;
  2. the needs and rights of individuals with disabilities;
  3. the roles health, education, and medical professionals assume in the rehabilitation of individuals with disabilities; and
  4. the qualifications for providing services.

- To promote excellence in the quality of service delivery among one's own and others' professions (e.g., eliminate time constraints and scheduling barriers, develop peer review systems).

- To recognize the need for and participate in activities that will ensure continued professional growth and competency, that is:

  1. To participate actively in one's professional organization;
  2. To advocate for the needs of individuals with disabilities and their families within one's profession;
  3. To participate in various activities that will facilitate continued growth of professional knowledge; and
  4. To promote appropriate interdisciplinary training of allied health professionals so as to meet the needs of and ensure the rights of individuals with disabilities.

4. **Roles and Responsibilities Related to Professional Practice--Coordination**

- To help coordinate efforts of health, education, and related services; that is:

  1. To understand other health, education, and related services professionals' roles;
  2. To work cooperatively with other professionals concerned with the services provided for children and youth;
  3. To be sensitive to and actively participate in coordinated and adaptive health-care planning for the life span of the youngsters;

4. To promote interdisciplinary pre-service teaming opportunities (e.g., shared curricula and field experiences);

5. To promote and, as appropriate, conduct research pertinent to clinical practice;

6. To read and publish in the journals of other disciplines;

7. To help develop effective alliances between various professional organizations and existing parent and consumer coalitions to promote the needs and rights of youngsters with disabilities; and

8. To advocate for funding from appropriate local, state, and federal agencies to train health professionals.

- To help develop and provide cost-effective programs and services.

- To identify and help implement creative approaches to funding programs for persons with disabilities (including community and business resources and consultants);

- To improve existing approaches to the delivery of health and education services through research and dissemination.

5. **Roles and Responsibilities Related to Professional Practice—Advocacy**

- To promote advocacy initiatives on behalf of youngsters with disabilities with other professionals.

- To promote and advocate for prevention of disabling conditions (e.g., pre-natal care; genetic counseling, etc.).

- To understand and be able to explain the dimensions and limitations of personal and professional advocacy and its intimate relationship with appropriate identification and referral procedures.

- To assist in consumer/client and parent involvement in advocacy efforts.

- To exert pressure for enforcement of existing laws at local, state, and federal levels.

- To promote regulation, legislation, and litigation on behalf of youngsters with disabilities and their families.

- To understand the political process and the implications of advocacy within one's work setting, community, state, and professional organization.

- To help establish and maintain geographical networks to promote access to services in underserved areas (e.g., transportation networks, rural service delivery networks, etc.).

- To help develop and/or modify educational standards to create access rather than barriers to individuals with disabilities who wish to enter the health, education, and medical professions.

6. Roles and Responsibilities Related to Communication

- To communicate effectively with individuals with disabilities and their families; that is:

    1. To convey information clearly and listen actively to individuals with disabilities and their families;

    2. To adapt messages according to the needs of the individual with a disability and his/her family; and

    3. To be sensitive to and adapt to the verbal and nonverbal cues which indicate concerns or problems related to the handicapping condition, whether expressed by parents, siblings, or the individual with a disability.

- To facilitate and effect appropriate interprofessional communication.

- To facilitate and effect appropriate inter- and intra-agency communication.

- To facilitate and effect appropriate communication between university/college training programs in health, special education, and regular education.

- To facilitate and effect appropriate communication with and between various state and/or federal agencies and governing bodies.

As noted earlier, these roles and responsibilities have been identified specifically for health professionals. Their relevancy for other professionals who provide services to youngsters with disabilities and their families (e.g., special educators, regular educators, physicians, nurses, etc.), however, are obvious and would be well-worth considering as all groups develop and evaluate pre- and in-service education programs.

The next unit will begin a detailed discussion of skills necessary for meeting these important roles and responsibilities--skills and strategies for effectively communicating with clients, their families, and colleagues. Each of the successive units will detail the health professional's roles and responsibilities in identifying youngsters with handicapping conditions, providing and coordinating appropriate referral mechanisms, and advocating on their behalf. In addition, each of the units provides recommended strategies for implementing these critical roles and responsibilities.

SUPPLEMENTAL READING

Featherstone, Helen. A Difference in the Family: Life with a Disabled Child. N.Y.: Basic Books Incorporated, Publishers, 1980.

Drawing on interviews with parents and professionals, her own experience, and materials published in autobiographies, this book presents a sensitive and compelling statement on the effects and consequences of a disabling condition on a family and their experiences. It deals with questions relating to barriers and interactions with physicians, teachers, and health professionals. The psychological reality and issues of communication within a family, as well as within the greater community are discussed. Ms. Featherstone clearly addresses her book both to parents and to those professionals who must manage the long-term implications of dealing with an individual with a chronic disability.

REFERENCES

Del Polito, C.M. "Roles and Responsibilities of Allied Health Professionals in Providing Services to Individuals with Disabilities and their Families," Advocacy Report, The American Society of Allied Health Professions, Washington, D.C., 1982.

Del Polito, C.M. "Multidisciplinary Education: Core Compentencies for Meeting the Needs of Youngsters with Disabilities," a paper presented at the Interprofessional Health Leadership Symposium, Gainesville, FL, April 7-9, 1983.

UNIT 3

Communication

CAROLYN M. DEL POLITO

UNIT 3: COMMUNICATION

PURPOSE AND OBJECTIVES

Purpose:

To understand the communication process, the professional's role in that process, and the implications of appropriate communication behaviors for the provision of health and education services to youngsters with disabilities and their families.

Specific Objectives:

At the conclusion of this unit, readers should be able to:

1. Discuss the implications of communication competence for the professional's role in the provision of coordinated health and education services for youngsters with handicapping conditions and their families.
2. Identify and discuss the barriers to effective communication with clients, their families, colleagues in health and education, and others concerned with the delivery of health and education services to youngsters with handicapping conditions.
3. Recognize and discuss the influence of others' perceptions of the health professional's role in identification, referral, and advocacy initiatives for youngsters with disabilities.
4. Discuss the impact children and youth with handicapping conditions can have on all family relationships and the implications for communication interventions.
5. Identify, promote, and implement appropriate, supportive communication strategies (verbal and nonverbal) when interacting with children and youth with handicaps, their families, and others concerned with the delivery of education and health-related services.
6. Identify and promote appropriate communication strategies to identify and use parents' knowledge and expertise in designing the youngsters' education and related-health program.

UNIT 3

Effective Communication: Process and Strategies for Health Professionals

CAROLYN M. DEL POLITO

The previous unit discussed the major barriers to the delivery of effective services and the roles and responsibilities health professionals must assume to help alleviate those barriers. Among the necessary competencies identified, one area continually emerges: the professional's **competence as a communicator**. Public Law 94-142 and the subsequent increasing demands for accountability, for cooperative teaming approaches, and for humanistic, individualized health and education programs for youngsters with handicapping conditions accent the need for effective communication.

In identification, referral, coordination, and advocacy activities, the professional's ability to use effective communication strategies--with clients and their families, as well as with peers, supervisors, and other health and education professionals--is critical to effective and coordinated service delivery (Del Polito, 1982). Further, it is not only what we say, but how we say it which can have a tremendous impact on the youngster's perceptions of him or herself, as well as the parents' perceptions of themselves, their child, and their service providers (Hamachek, 1971).

In the list of roles and responsibilities presented earlier in Unit 2, experienced health professionals across the country emphasized the importance of developing and using effective communication strategies, particularly in intrapersonal and interpersonal communication, small group processes, and conflict resolution. Training in persuasion and advocacy also were recommended. The specific communication skills identified for all service providers included:

A. To communicate effectively with individuals who have disabling conditions and their families; that is:

   1. To present information clearly and listen actively to individuals with disabilities and their families;

   2. To adapt messages according to the needs of the individual with a disability and his/her family;

   3. To use appropriate problem-solving, assessment, and observational techniques, including effective verbal and nonverbal listening behaviors for identification and referral of youngsters with special needs;

   4. To adapt to the verbal and nonverbal cues which indicate concerns or problems related to the handicapping condition, whether expressed by parents, siblings, or the youngster with a disability; and

   5. To establish and maintain effective relationships which exhibit sensitivity to, respect for, and trust and cooperation with youngsters and their families.

B. To facilitate and effect appropriate interprofessional communication; that is:

   1. To evaluate the role of communication in the service delivery process; and

   2. To develop and maintain effective teaming, negotiating, and consulting skills in interactions with colleagues, supervisors, parents, as well as with other professionals in health and education who are concerned with meeting the needs and rights of all youngsters.

C. To facilitate and effect appropriate inter- and intra-agency communication.

D. To facilitate and effect appropriate communication with and among university/college training programs in allied health, special education, and regular education.

E. To facilitate and effect appropriate communication with and between various state and/or federal agencies and governing bodies.

As reflected in the above list, a health professional's competence as a communicator--whether in intrapersonal contexts (e.g., personal growth and development) interpersonal contexts (e.g., teamwork, consultation, negotiation, assessment), or presentational contexts (e.g., informative or persuasive presentations)--plays a significant role in the service delivery process.

These competencies emphasize the need for a cognitive or **knowledge base** in communication: health professionals must understand (a) the communication process, (b) the professional's role in that process, and (c) the implications of appropriate communication behaviors for the provision of health and education services. Similarly, the competencies stress the need for an **affective base**: a sensitivity to the verbal and nonverbal cues which occur in the service delivery process. Finally, these competencies emphasize a behavioral or **performance base**: an ability to implement and model communication behaviors which are appropriate for the persons and issues involved and the context of the situation.

This unit cannot provide the health professional with answers to all questions related to communication competence. The scope of this publication is limited; it will provide, however, a **framework** for understanding the implications of communication competence for the professional's role in the provision of coordinated health and education services for youngsters with handicapping conditions and their families by examining (a) the process of communication; (b) barriers to communication effectiveness; and (c) strategies for enhancing communication effectiveness.

THE COMMUNICATION PROCESS

Competence as a communicator is critical to providing appropriate services to youngsters with handicapping conditions and their families. One's **knowledge** of the communication process, **sensitivity** to all verbal and nonverbal cues, and **ability** to select and model appropriate communication behaviors are central to provider-client communication.

In studying the communication process during the past thirty years, communication scholars have moved from the definition of communication as the transmission of information (message-centered) to a definition which focused on the transfer of information from one person to another (speaker-centered), and finally to an understanding that communication must be defined in terms of the **meaning** the receiver attaches to the incoming stimuli (meaning-centered).

This meaning-centered approach focuses on communication as a dynamic, on-going, **circular** process which is constantly changing (Barnlund, 1971). This definition emphasizes the complexity of the process, recognizing communication is not limited to message formulation in speaking and message reception in listening, but rather involves the participants' total personalities in a **transaction** in which messages are sent and received simultaneously.

Communication transactions are complicated by the history of experiences each participant brings to the situation, including a history of perceptions--of themselves, of the other person, and of the other's perceptions of them. Within the health care arena, complications multiply with the many persons providing services to an individual client: transactions occur between provider and client, provider and parents, client and parents, and all other persons impacting the service delivery system (e.g., supervisors, siblings, aides, and other health and education professionals).

Thus, health care professionals who are concerned with humanistic, coordinated services adapted to the unique needs of youngsters with handicapping conditions must be able to select, adapt, and implement speaking and listening behaviors appropriate for the purpose, the listeners, and the context of the interaction.

> Consider the case of a bright, young physical therapist who was puzzled when she learned the well-educated parents of a two-year-old client did not follow up on her recommended referrals to other health and education professionals. Perhaps, if the physical therapist had evaluated her communication behaviors with the parents and child, the reasons for the parents' inaction would have been evident.
>
> An evaluation of the transaction might have revealed an inappropriate use of vocabulary, organizational approach, rate of speech, or clarifying or supporting data with the parents. Perhaps her nonverbal interactions with the child (e.g., seemingly rough handling with little verbal interaction with the child) lacked sensitivity. Perhaps, the therapist's inability to perceive accurately or adapt to the child's capabilities or the parents' nonverbal reactions, including their facial expressions, tension, and inattentive behaviors, provoked the parents' failure to follow-through on her recommendations.

The ability of even well-educated parents to comprehend a professional's instructions or recommendations may be limited by the context of the situation. Suppose, for example, these well-educated parents have taken their only child for a routine check-up before leaving for a vacation when they unexpectedly receive a diagnosis of their child's disabling condition. Not only are they unprepared for such news in this context, but they are likely to be unfamiliar with the causes and prognosis of the condition, the health providers' training and expertise in the area, and the effects of the diagnosis on their lives and the life of their child.

Examples of ineffective and insensitive communication strategies abound in our clinics, hospitals, and classrooms. Increased interaction among health and education professionals, parents, and youngsters in the assessment of handicapping conditions, in the development of IEPs (individualized education programs), in due process procedures, and for other requirements of Public Law 94-142 have emphasized the need for improved communication in the delivery of services.

While there are no easy answers to ensure accurate message interpretation by professionals or clients, health care providers can prepare to facilitate more appropriate, effective communication transactions with their clients and colleagues. To do so, they must understand the **communication process**, and be prepared to select, implement, and evaluate communication strategies appropriate for the receivers, themselves, and the situation. **Knowledge** of communication behavior and strategies is insufficient; one also must be able to **demonstrate** that knowledge in a given situation. Only with such **communication competence** will health professionals be able to better control the meaning attached to the messages sent and received in their clinics, hospitals, and classrooms.

To understand the communication process between two or more persons (whether with a client, a small group of colleagues, or with a large audience in a public speaking or mass media situation), it is helpful to review the most basic, and perhaps the purest form of communication: communication with one's self, as illustrated in the **intrapersonal communication** process.

Intrapersonal Communication

As noted in Figure 1, one of the most critical elements in the communication process is the individual's **selectivity** in exposure, attention, perception, and retention of stimuli which bombard the senses. The situational climate, which includes time, place, context, persons involved, and their motivations, provides a wide array of stimuli from which the individual selects for interpretation. Stimuli may be external (visual, aural, tactile, gustatory, or olfactory) or internal (physical or psychological), as the following example illustrates:

> As Nancy walks down the street in the early morning on her way to the clinic, she may choose to attend to other people's smiles and the beauty and perfume of the trees with their spring buds, or she may select to attend to her empty stomach, other people's frowns, and her meeting with her supervisor scheduled for 8:30. While physical attributes, such as hearing loss or blindness, may limit the acuity of Nancy's senses, nonetheless, the stimuli she selects to attend to, interpret, and respond to will be congruent with her perceptions of--and particularly her acceptance of--herself and her world.

One's perception of self or self-concept, then, is **central** to the communication process, whether it is communication with one's self

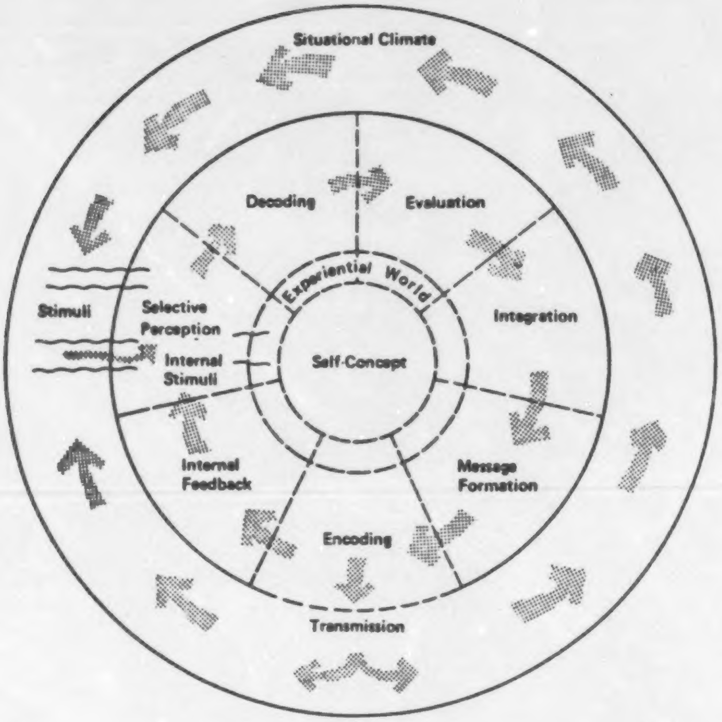
Situational Climate
Decoding
Evaluation
Experiential World
Stimuli
Selective Perception
Integration
Internal Stimuli
Self-Concept
Internal Feedback
Message Formation
Encoding
Transmission

Figure 1. The intrapersonal communication process.

Figure 1 illustrates the intrapersonal communication process. An individual's self-concept is at the heart of the process, since one's self-concept determines the stimuli selected and the way in which the stimuli will be decoded, evaluated, and integrated into the individual's self-system. The self-concept also determines the message to be transmitted and how it will be sent. As the dotted lines indicate, the self-concept affects and is affected by one's experiential world --all the information accumulated during one's lifetime, including cultural experiences, knowledge, abilities, beliefs, attitudes, and feelings, as well as needs, goals, and expectations for the future. In turn, the person's experiential world affects the entire process of intrapersonal communication. As Figure 1 indicates, the process is ongoing, circular, and operates as long as stimuli from the situational climate (time, place, and circumstances) or experiential world bombard the individual. (Del Polito, 1977, page 3.)

in intrapersonal communication or with others in interpersonal communication. An individual's evaluation of self physically, socially, and intellectually will influence how he/she perceives others, accepts others, and therefore, how he/she chooses to commmunicate with them.

Thus, in the earlier example, the young physical therapist selected only those stimuli which reinforced her perception of herself as an effective practitioner. She selectively attended to and decoded only those verbal and nonverbal cues which she could integrate with her past experience and interpret as approval for a job well-done. She selectively sought out and interpreted the parents' facial expressions, head nods, and questions as evidence of their understanding and acceptance of the information she presented. Behaviors which did not support her perceptions, such as tension, blank stares, and inattentive behavior, were not attended to, and thus not perceived as relevant in the interpretation of the communication transaction.

Meaning attributed to communication with oneself (in intrapersonal communication) and with others (in interpersonal communication), therefore, is dependent upon subjective perceptions, which, in turn, are based upon individual **experiential worlds**. Consider an IEP meeting in which the communication transaction is compounded by four or five different health and education professionals, simultaneously interpreting the physical therapist's message, each from a unique perspective. Each practitioner will select and interpret the others' cues from an experiential world which includes different cultural experiences, knowledge, mental and physical abilities, beliefs, attitudes, and feelings, as well as different individual needs, goals, and expectations for the IEP meeting outcome and the youngster's future (Del Polito, 1977).

In many instances, communication is restricted to verbal directions, with limited nonverbal facial and hand gestures. Communication transactions, however, may include a variety of verbal and nonverbal communication codes. Nonverbal codes may include facial and eye expressions, inflection, touching behaviors and sign language, while verbal codes may include **spoken** language in the form of script, typed, or Braille symbols. Yet whatever code of communication we employ, whatever situation we communicate in, the process remains relatively the same. The **meaning** of the communication will be determined by the receiver's perception of the message based on his/her experiences, knowledge, beliefs, needs, and expectations in relationship to the purpose, the sender, and the situation.

Role of Self in the Communication Process

Basic to one's perceptions, acceptance, and understanding of others are the perceptions, acceptance, and understanding of one's self. Understanding **self-concept** theory and the critical role it assumes in the communication process, then, is basic to improving communication competence--in terms of the professional's perception of self, the impact of that self-perception (self-concept) on the communication transactions with clients and others in the service delivery process, and, more consequentially, on the young clients' perceptions of themselves.

In an examination of self-concept theory, four basic propositions emerge which reinforce the importance of understanding the relationship of self-concept to communication in our transactions with others:

1. Self-concept, one's total perceptual appraisal of oneself--physically, socially, academically, and psychologically, **guides and directs behavior**, and, thus, our communication with others.

2. An individual's self-concept can be modified or changed in certain social interactions.

3. Although there are a variety of ways self-concept develops (e.g., societal **labeling** of dominant behavior patterns and **social comparisons**), self-concept develops primarily through interactions (**communication**) with others.

4. The more influential interactions are those involving **significant others**--those persons who provide rewards and punishments and who reinforce the individual's perception of him/herself (Del Polito, 1973).

For many youngsters with handicapping conditions, health professionals provide feedback to the youngsters regarding their abilities through both verbal and nonverbal interactions--whether through eye-contact, a smile or a frown, a pat on the back, or through a sharp negative verbal response to a practiced activity. Through the health professional's communication behavior (intentional or nonintentional), therefore, the young client continually and selectively perceives evaluation data about him or herself. Consequently, if perceived by the youngster as credible and personable, the health professional can become a significant person in the development, maintenance, and, hopefully, **enhancement** of the youngster's self-concept (Del Polito, 1977).

A youngster's perceptions of self and his/her feelings of self-esteem--feelings of ableness, worthiness, and confidence--therefore, are determined in many instances by the health professional through his/her communication transactions with the youngster, particularly if transactions are frequent and long-term. It is not uncommon for able-bodied health professionals with limited personal experiences with disabilities to interpret the youngster's verbal and nonverbal behaviors as inappropriate and, therefore, perceive the youngster as less credible and less competent than he/she actually is.

As discussed in the **Introduction**, whether or not the child is labelled "handicapped," a stigma or differentness attributed to any child places that youngster in a severe social disadvantage. This is true particularly when the differentness interferes with the youngster's communication style (e.g., speech impairment, cerebral palsy, hearing impairment, visual impairment, learning disability). If, as contended earlier, the health professional focuses on the "differentness"--the handicap--and not the youngster as a whole person, the youngster will maintain negative self-perceptions, further affecting his/her ability to communicate and "to assume virtually any positive social persona" or "normal social functions" (Gliedman and Roth, p. 23). The youngster's positive or negative feelings of self-esteem similarly will affect his/her feelings about others generally, as well as determine his/her responses to treatment programs.

Likewise, just as clients look to the health professional's verbal and nonverbal cues for approval and for validation of themselves as worthy, competent individuals, so too do health professionals, as adults, continually evaluate themselves in terms of societal criteria, comparisons with others, and the verbal and nonverbal feedback received from others--particularly persons perceived as credible and concerned, including supervisors, colleagues, **and** clients. Thus, perceptions of self as a health care provider and as a communicator rank extremely high in determining interaction patterns and behaviors with clients, with their parents, and with colleagues. Competence as a health professional, then, is influenced by one's concept of self as a communicator which is determined by one's perceptions of societal rules or norms for effective communication interaction behavior, as well as comparisons of one's communication style with others' styles.

Because a health professional's competence as a communicator can have a significant impact on the development of a client's self-concept, affecting his/her future academic, career, and social success, health care providers need to reinforce self-concept enhancement behavior and activities with their young clients. In so doing, professionals must realize that an enhanced self-concept is not an inflated view of oneself, but rather a realistic perception of one's strengths and weaknesses, **and** an acceptance of that perception. One method used to enhance youngsters' self-concepts is to discuss self-concept theory with them so that they understand how and why they perceive themselves and their abilities as they do. (For a more detailed review of self-concept theory, see Gergen, **The Concept of Self**, 1971).

A second approach recommended to enhance youngsters' perceptions of themselves deals with the professional's style of interaction with the youngsters and their families. Supportive, humanistic behaviors which communicate understanding and acceptance will impact the youngsters' and their families' perception and acceptance of themselves, one another, and their service providers, further influencing their overall behaviors with others. Critical to this approach, however, is the professional's ability to evaluate realistically his/her competencies as both communicator and care provider, accept both strengths and weaknesses, and work to improve those competencies. Specific strategies for assessing and enhancing communication competence are presented later in this unit. First, however, it is helpful to understand some of the impediments to effective communication which can occur in any situation.

BARRIERS TO COMMUNICATION EFFECTIVENESS

Within any situational environment, there are numerous opportunities for messages to be misinterpreted or selectively filtered. Barriers in the communication process, commonly known as "**noise**," occur throughout the process and refer to anything which interferes with accurate message interpretation. While music practice in the occupational therapy room next door may interfere with a client's hearing and understanding instructions, so too will an upset stomach, reliving last night's date, or an anxious on-looking parent. Within health and educational environments where a variety of professionals must coordinate their activities and services for individual clients, the noise can become maddening, resulting in segmented, inefficient, and costly delivery of services.

There are numerous noise variables which can affect the messages a health care professional selects to attend to and interpret. Included among those identified by Hurt, Scott, and McCroskey (1978) are: physical or sensory limitations; attention spans; learned habits; expectations; anxieties and conflicts; social and physiological needs; attitudes, beliefs, and values; and message elements, such as organization and language use (pp. 73-80). Thus, an overly hot or cold room, the sound of passing trains, physical mannerisms of the communicator, unfamiliar vocabulary, mumbled articulation, hunger, yesterday's fight with a best friend, or a new snowfall could be classified as "noise" if selectively attended to and, consequently, interferes with the intended message.

While one might assume sensory limitations such as a hearing loss or a learning disability would create the greatest barriers in communicating with persons with handicapping conditions, in practice, the greatest difficulties are caused by the "attitudes, beliefs, and values," along with the "expectations" and "learned habits" of attributing stereotypical or similar characteristics to unfamiliar persons, objects, or concepts (Hurt, Scott, and McCroskey, 1978, p. 73-80).

Of particular significance is the way society generally perceives and "defines" a handicapping condition. As discussed in the **Introduction**, most Americans have similar attitudes toward all persons with disabling conditions regardless of the person's specific impairment. Further, even though "more than fifty percent of the people in the United States publically express positive attitudes toward disabled persons, most people perceive handicapped persons as in some way different and inferior" to able-bodied individuals (Yuken, 1981, pp. 2-3).

Unfortunately, the same perjorative attitudes, beliefs, and values and the accompanying myths and stereotypes held by society as a whole are reflected in the experiential worlds of providers and clients. These attitudes are evidenced in "interpersonal relationships, in media presentations, in language, and in the organized structure of health and education policies" (Del Polito, 1982, pp. 3-4). The resulting discrimination, handicappism, has been equated with the discrimination of racial, ethnic, and other minority groups--a form of noise causing the greatest barrier to accurate message interpretation.

Labelled by their disability, persons with handicapping conditions tend to be treated differently and expected to behave differently as well. The "differentness" or stigma attributed to persons with disabilities presents social, psychological, and communication problems for those with impairments.

> In reporting major research findings related to the nonverbal communication patterns of children with learning disabilities, Lieb-Brilhart (1982) supports this contention. Peers, strangers, as well as parents and teachers were found to perceive the social behavior of learning disabled youngsters negatively and, in the case of teachers, react differently to youngsters with learning disabilities than to their non-disabled peers (Del Polito, 1982, p. 4-5).

In fact, as noted in the introduction to this book, attitudes of health and education professionals working with persons who have handicapping conditions tend to be more discriminatory than other persons not so involved. More serious charges are levied against health professionals who tend to perceive the youngster only in relation to the disability--the blindness, the stuttering vocal sounds, the braced legs--not as a whole person.

Thus, each of the noise variables discussed so far (e.g., attention span, language use, sensory limitations, attitudes, etc.), can become a barrier to effective communication, affecting the individual's selective exposure, perception, attention, and retention of messages, and can promote stereotypical responses. Each of these "noise" variables, then, can lead to other, more commonly-recognized behavioral listening problems, such as:

- viewing the topic as uninteresting;
- criticizing the speaker's delivery instead of the message content;
- listening only for facts;
- tolerating or failing to adjust to distractions; and
- listening only to what is easy to understand (Barker, 1971).

A critical "listening" impediment, however, triggered by these conditions, is what Gibb (1961) has termed, "defensive listening."

Rather than attending to the message as intended by the speaker, the listener may become frustrated, argumentative, or may "tune out" the speaker completely. **Defensive listening** is aroused when the receiver perceives or anticipates threat. According to Gibb (1961), rather than listening to understand, the receiver focuses on how he/she may dominate, impress, win, or escape threat or punishment. Defensive listening may occur any time the listener selectively perceives evaluation, control, hidden motivations, dogmatism, superiority, or little concern for him/herself as a person.

For example, a young client with cerebral palsy may perceive comments about his appearance to be his occupational therapist's way of exhibiting her superiority and righteousness, when, in fact, the therapist genuinely wanted to compliment the youngster for his taste in ties. Whether intentional or not, therefore, communication behaviors which are interpreted by the listener as "controlling" can create a defensive listening posture (facial, gestural, and verbal cues) which, in turn, raises the level of defensiveness in the original communicator. The more defensive one becomes, the less accurate are subsequent perceptions of the speaker's actual messages and, therefore, the less effective the communication. For health professionals, it is important to recognize defensive listening behaviors which may surface among clients, colleagues, or themselves because of past experiences, or anxieties about the current situation. A supportive, yet realistic environment can enhance the participants' feelings of comfort and confidence. Specific strategies will be discussed in the next section.

The health professional's verbal and nonverbal reactions to and communication with the "different" youngster, therefore, indeed may provoke substantial **noise** in the communication transaction. The subsequent effect on the youngster's self-concept, communication competence, academic achievement, and future career success, then, are within the influence of the health professional and his/her competence as a commmunicator. As prospective models for their clients and colleagues, health professionals need to examine their own attitudes, values, beliefs, expectations, and learned habits and the influence these variables have on their interactions with **all** clients--

irrespective of their race, sex, ethnic or cultural background, or handicapping condition. Similarly, professionals in the health care system should be prepared to engage colleagues and clients in discussions regarding the impact of their experiential worlds and self-concepts on their attitudes and behaviors toward themselves and others, regardless of their individual differences.

In summary, there are three major communication axioms which often are disregarded and consequently create many of the barriers identified in this section:

1. **Communication is transactional.** Communication is a complex, circular process with participants who are constantly changing.
2. **One cannot NOT communicate.** As human beings we continually project nonverbal cues. Even while sleeping or staring blankly into space, we communicate messages to ourselves and others.
3. **Meanings are in people, not in words.** As repeated throughout this unit, it is not what is said, or how it is said, but rather the receiver's interpretation of the message cues, with the receiver's interpretation necessarily limited by his/her experiential world.

The next section will examine and recommend strategies for alleviating many barriers to effective communication and will provide suggestions for enhancing the professional's competence as a communicator. Obviously, this unit can only outline the needed competencies. Too, health educators and practitioners can not, and should not, assume responsibility for all communication training. Rather, with the assistance of this unit, health educators and practitioners can consult with colleagues in communication, psychology, and/or counseling programs in their higher education institutions to design training programs most appropriate for health care specialists' needs and responsibilities.

ENHANCING COMMUNICATIVE EFFECTIVENESS

To help alleviate some of the barriers previously discussed and to improve communication effectiveness with clients, colleagues, and supervisors, health professionals can develop and improve their competencies as communicators. As defined earlier, **communication competence** involves selecting, adapting, and implementing communication behaviors appropriate for the purpose, audience, and context of the situation.

In an important review of research related to communication competence, a report of the Speech Communication Association (SCA) (Allen and Brown, 1976) outlined a functional or pragmatic approach for improving communication competence, identifying five dominant uses of language or **communication functions** which instruction should emphasize:

1. **Controlling:** Communication acts in which the participant's dominant function is to control behavior; for example, persuading, commanding, offering, suggesting, permitting, threatening, warning, prohibiting, contracting, refusing, bargaining, rejecting, acknowledging, justifying, and arguing.

2. **Expressing Feelings:** Communication acts which express and respond to feelings and attitudes, such as exclaiming, expressing a state or an attitude, taunting, commiserating, tale-telling, blaming, disagreeing, and rejecting.

3. **Informing:** Communication acts in which the participant offers or seeks information; for example, stating information, questioning, answering, justifying, naming, pointing out an object, demonstrating, explaining, and acknowledging.

4. **Ritualizing:** Communication acts which serve primarily to maintain social relationships and to facilitate social interaction, such as greeting, taking leave, participating in verbal games (pat-a-cake), reciting, taking turns in conversation, participating in culturally appropriate speech modes (for example, teasing, shocking, punning, praying, playing the dozens), and demonstrating culturally-appropriate amenities.

5. **Imagining:** Communication acts which cast the participants into imaginary situations and include creative behaviors such as role playing, fantasizing, speculating, dramatizing, theorizing, and storytelling.

The SCA report emphasized the interactive nature of each of these functions for both the sender and receiver. In a controlling or persuasion context, an individual may assume both the role of controller and the one being controlled. Thus, while the nutritionist in a community hospital may recommend and wish to persuade the physician of a client's need for solid foods, the physician may reject the nutritionist's point of view and retain control over the situation.

> If we are being controlled, we need to be able to recognize the other's intention and its appropriateness to the particular context. We must also have a repertoire of behaviors that can confirm for the other that we recognize that intent and assent to it (Allen and Brown, 1976, p. 250).

Focusing on the five communication functions provides a framework for improving communication competence, as well as a relevant approach for enhancing one's effectiveness in all forms of communication: reading, writing, speaking, and listening. A program designed to improve one's persuasion or control strategies in a face-to-face interpersonal situation, for example, also would improve one's skills in writing to a congressional leader regarding one's perspective on an issue, as well as in presenting one's recommendations before an IEP Committee. Similarly, as one improves his/her ability to "persuade" others, skills in recognizing others' persuasion or controlling strategies are enhanced. By utilizing the five functions of communication and the recommendations for enhancing communication competence which follow, personalized improvement programs can be designed by the health professional in collaboration with colleagues from appropriate departments/programs on college campuses.

Three skills which are basic to any improvement program designed to enhance communication effectiveness are: **social sensitivity, active listening**, and **honest communication** (Del Polito, 1973; 1977; 1983). These three supportive communication skills are critical to the health professional's ability to understand self and others, to obtain and utilize feedback from others, and most importantly, to adapt and implement appropriate strategies for each of the communication **functions** in any communication **context.** Contexts may include interactions with one other person, with small groups of persons in team or problem-solving sessions, or with large groups in lecture, discussion, and/or mediated presentations. The following paragraphs describe these skills; a sample exercise is provided in Appendix 3A.

Social sensitivity refers to one's ability to empathize with the other person: to see, feel, and hear with the other person; to step into the other person's shoes and see the world from his/her perspective; and to understand the feelings, thoughts, needs, and goals of the other person. Maximum understanding through social sensitivity occurs when the listener:

1. Understands the speaker's perceptual world, including the speaker's attitudes, values, beliefs, knowledge, culture, social system, past experiences, and future expectations;

2. Understands his/her own perceptual world and selectivity processes;

3. Understands the content communicated--**what** is said; and

4. Understands the **feelings** communicated--**how** the message is said.

To empathize with and become sensitive to the other person, one must listen actively. **Active listening** demands total commitment to the communication interaction. Active listening implies waiting until the other person completes his/her statement to understand the situation as seen by the speaker. It suggests no evaluation, judgment, agreement, or disagreement. For example, the health professional, as active listener, conveys acceptance of the client, along with acceptance of his/her ideas, attitudes, and values. To confirm an understanding and acceptance of the client during active listening, the professional should communicate "attention" during the interaction both nonverbally through attentive posture, head nods, eye-contact, facial expressions, and verbally through vocalizations which indicate interest in the client's comments. In addition, through paraphrasing, supportive comments, and nonverbal reactions, the health professional reflects his/her understanding of the client's ideas, concerns, and feelings. Providing feedback in the form of reflective responses aids in reducing client defensiveness and in keeping all channels of communication open. (See Appendix 3A for a reflective response exercise.)

In addition, communication which is spontaneous and honest also reduces defensiveness. **Honest communication** does not mean indiscriminate frankness; rather it implies revealing some of one's normally hidden self to others, through expressions of ideas, feelings, and attitudes. A health professional's ability and willingness to be open with others, whether with clients, parents, or colleagues, will encourage others to trust them and to communicate openly and honestly with them, and with all others with whom they interact.

Since honest communication is facilitated by self-disclosure, health professionals should be prepared to recognize and facilitate appropriate disclosure behavior. Specifically, they should understand that disclosures should be (a) appropriate to the situation and to the relationship, and (b) presented only in settings of good will and trust. Because there is risk involved in the sharing process, an atmosphere of warmth and trust must be developed to encourage information sharing (e.g., sharing attitudes, concerns, interests, perceptions, likes and dislikes, fears, hopes, and anxieties). Health professionals must recognize that each participant controls when, what, how much, and to whom to disclose. Again, information about the self should be disclosed in contexts appropriate to both the situation and the relationship. Thus, through sensitivity, active listening, and honest communication, the experiential worlds of each participant in the communication transaction expands, increasing the likelihood of understanding, acceptance, and more effective communication.

Gibb (1961), in providing suggestions to help alleviate defensive listening behaviors, reiterates the need for sensitive, active, and honest communication. More specifically, he recommends supportive communication behaviors which include the following:

1. A problem-solving orientation, in which professional and client (and/or parents) collaborate on seeking solutions to problems;

2. Genuine requests for information, rather than implying that others need to change their behaviors;

3. Spontaneity--honest and straight forward communication; and

4. Empathy and equality--willingness to share feelings and exhibit trust and respect for others, placing little importance on differences in abilities or expertise.

Similar characteristics and conditions were identified by patients as necessary for **humanized** health care. In addition to being treated as unique and irreplaceable human beings, inherently worthy of the caregiver's concern, patients want to be able to exercise control and share in the decisions affecting their care. Further, they desire interactions with health care providers who exhibit empathy and warmth in a reciprocal and non-patronizing relationship with them (Howard and Strauss, 1975).

Table 1 outlines a basic approach for solving problems together with one or more persons, allowing all concerned parties to participate in the decisions which affect them. This problem-solving process, therefore, can and should be used not only with clients and their families, but with any and all others (health, education, and social services professionals) involved in decisions affecting the youngster's diagnosis and treatment program. Often, the demands of the health care and educational systems appear to press the care providers for immediate decisions, identified by McCullough (1982) as **reflective urgency**. The need, however, is for **reflective thinking** which requires an open-minded, equal hearing to all points of view. Thoroughness, accuracy, considered judgment, lively imagination, sensitivity to the feelings of others, and patience--all should be part of the decision-making process.

> Once a solution/decision is selected, the decision-maker needs to be able to articulate and defend the reasoned arguments to others within the system, be they the patient/client, the family of the client, other care providers, or third-party payers (Del Polito, 1983, p.8).

Table 1

THE PROBLEM-SOLVING PROCESS

1. **Awareness of the Problem**
    a. Significance and immediacy of the problem
    b. Effects on individuals involved
    c. Broader implications for the group
    d. Need for decision or action

2. **Definition of the Problem**
    a. Problem clearly stated
    b. Terms clearly defined

3. **Exploration of the Problem**
    a. Nature and extent of the problem
    b. Causes of the problem
    c. Effects of the problem
    d. Main issues
    e. Possible limitations

4. **Criteria for Solution**
    a. Criteria identified and adopted for evaluating possible solutions
    b. Criteria = Limitations which are placed on the solution (e.g., funds, employer's policy, professional obligations)

5. **Suggestions of Possible Solutions**
    a. Brainstorming all possible solutions
    b. Possible solutions should reflect thoughtful, realistic, and representative proposals for decision or action

6. **Exploration of the Possible Solutions**
    a. Implications of each possible solution
    b. Best solution meets most of the criteria identified

7. **Solution Implementation**
    a. Focus on strategies to put solution into effect?
    b. To implement solution, the problem-solving process is repeated.

Strategies for improving one's skills in the problem-solving process as well as in all other aspects of communication are provided in the design of the improvement program described below.

Improvement Program

Communication behaviors within and across all **functions** of communication (controlling, informing, expressing feelings, ritualizing, and imagining) can be improved. Recommendations from the Speech Communication Association's (SCA) report on developing communication competence (Allen and Brown, 1976) are integrated with Del Polito's (1976) recommendations for enhancing self-concept as a communicator, providing the following methodology for improving the communication competencies of health professionals. Similarly, this approach can and should be incorporated by service providers for use with **their** clients.

1. **Conduct realistic, objective evaluations of communication behaviors.** Accurate, objective feedback which considers knowledge and abilities in communication as well as content expertise should be sought from competent sources (a) to understand one's true strengths and weaknesses, (b) to accept those strengths and weaknesses, and (c) to modify behaviors to achieve desired competence. With the assistance of expert communicators (perhaps through alliances with departments/ schools of communication/speech), current repertoires of communication acts (across functions) of the health professional can be inventoried and assessed.

   The communication repertoire of a health professional will include the strategies selected for such communication acts as: presenting information, active listening, leading and facilitating group discussions, asking and responding to questions, presenting and defending arguments, and resolving technical and ethical conflicts.

   Appropriate communication strategies or approaches selected for each of these acts will vary depending on the person(s) with whom the health professional interacts, (e.g., parent, child, colleague, supervisor) and the context of the situation (e.g., business or social). Understanding the communication process, the context of the interaction, and the audience should guide the professional in making appropriate strategy decisions.

As skills and abilities within the health professional's repertoire are assessed, personal goals then can be designed to expand the repertoire where desired.

2. **Establish realistic communication goals.** Recognizing the extent of one's repertoire and the skills yet to be developed, with the assistance of a communication expert, the health professional should identify an area which he/she wishes to improve and design goals which are **meaningful**, **challenging**, **attainable**, and **clearly defined.**

   To maximize success in expanding one's repertoire in a particular communication mode (for example, asking questions, giving instructions, or leading small group discussions), the strategies selected should be **planned**, **practiced**, and **evaluated** across content areas. Time should be designated for practicing communication skills--with peers, superiors, clients, and their families.

   Feedback obtained from an instructor and colleagues can be most helpful if provided in an atmosphere of trust and in a spirit of assisting the "performer" to improve technical expertise and communication competence. In addition, using videotaped playbacks of presentations/interactions in conjunction with audience feedback proves to be an excellant tool for allowing the communicator to observe the product of planned strategies and to make decisions for modifying future behaviors. Again, consultation with colleagues in communication should be sought for assessing both the effectiveness of the communication behaviors and the strategies selected.

3. **Concentrate on improving communication competencies, not perfection.** Striving for perfection increases the opportunities for the communicator to experience failure for not achieving the "perfection" goal. It is critical, therefore, for health professionals to focus on strategies which would help them to improve, not to become "perfect." This does not suggest avoiding failure at all costs, but rather, to learn from mistakes, and to concentrate on modifying behaviors to improve the communication transaction. Developing communication competence is an on-going process.

4. **Identify, accept, and promote personal communication strengths.** "Positive self-evaluation in the form of verbal reinforcements" is positively related to an enhanced self-concept (Del Polito, 1977). Once identified, strengths should be accepted and praised. While self-praise often is equated with the negative behaviors of bragging and boasting, unless health care providers can accept themselves and their strengths in their various roles--as communicators, health professionals, siblings, dancers, friends, writers, etc.--the less likely they will be to accept others and their strengths. Without self-acceptance, one's understanding of the other person is limited, thus diminishing the opportunities for truly effective communication. Often, too, when professionals negate their true accomplishments in communication, they do not learn from those accomplishments or expand their repertoires in the skill areas.

5. **Accept and promote others' strengths and assist others to accept and praise themselves.** This last recommendation repeats the need to assist others in recognizing and accepting themselves--as persons and as communicators. Praise, in all cases, must be accurate, honest and appropriate, and focused on specific behaviors in the context of the situation.

These recommendations emphasize the need to **evaluate** continually the effectiveness of the strategies employed in each communication transaction, whether in a telephone conversation with a parent, a lecture presented for the fifteenth time and third year in a row, an IEP conference, or interactions with a client for diagnosis, assessment, or program implementation. For those communication transactions for which pre-planning can occur, a conscious effort in the design of the communication is recommended, particularly for the health professional in training.

Selecting appropriate strategies and discussing them in a written personal log or with colleagues can focus the professional's attention on the rationale for all details of the communication act, and can be incorporated into daily activities within and outside the work environment. The questions which follow can be applied to any communication event. Basically, the health professional's concern should focus on the receiver--whether client, parent, or colleague, and adapting the message to his/her experiential world. All aspects of the message--communicator style, organization, supporting data, nonverbal cues, et cetera--should be adapted to the receiver(s), and appropriate for the purpose and context of the situation (Del Polito, 1977).

Recommended Strategy Questions:

1. What is the issue to be addressed? Why is it relevant for my presentation/interview/discussion?

2. What qualifications do I have to present/discuss this issue?

3. How should this message/presentation/interview/discussion be organized? Why is this the best organizational approach?

4. What main points should be stressed? Why?

5. What types of information should be used to support my position and best fulfill my purpose? (Examples: case studies, statistics, referenced quotes, illustrations, etc.)

6. How should the issue be introduced? Why use this particular approach?

7. How should the audience (of one or more persons) be involved? What strategies can be used to adapt to their needs, interests, values, and motivations?

8. How should the presentation/interview/discussion be concluded? Why use this conclusion?

A brief, topical outline can be used in planning to insure an organized, clear message, as well as to help evaluate the approach.

Similarly, evaluating the communication event in written form directs the health professional's attention to what **actually** occurred. In many cases, if the transaction was less than desired, one would prefer to forget it, rather than focus on the specific strategies which were and were not effective in accomplishing the desired goal. The suggested questions listed below should be answered following any communication event.

Recommended Evaluation Questions:

1. How well was the strategy plan followed?
2. Was the strategy effective?
3. What went wrong?
4. What went right?
5. What personal goals should be emphasized in the future?
6. What needs to be done to improve the next similar interaction and insure a more effective communication transaction?

In addition to the above recommendations, guidelines to enhance the self-concepts of youngsters with handicapping conditions are included in Appendix 3B. These guidelines, based on relevant theoretical and experimental literature, should assist the health professional in designing an effective communication environment (Del Polito, 1973). Further, Appendix 3C provides health professionals with tips for interacting with youngsters who have special needs. Along with general recommendations, specific suggestions are provided for a variety of handicapping conditions, including learning disabilities, mild retardation, communication disorders, hearing impairments, visual impairments, and orthopedic impairments. By incorporating these strategies, health professionals will enhance their clients' self-concepts, which, in turn, will impact their behavior, their programmatic achievement, and their overall satisfaction with the treatment program.

Conclusion

If youngsters--exceptional and nonexceptional alike--are to achieve their full potential, considerable attention should be given to the professional's communication competence, in understanding the communication process, and in implementing appropriate communication strategies. While it has not been the purpose of this unit to detail the specifics for conducting interviews or assessments, presenting treatment recommendations or lectures, leading discussions, or other communication acts, basic principles for a variety of communication activities have been identified. In addition, excellent texts have been written on each of these topics; several are recommended in the bibliography. Readers are urged, however, to consult with colleagues in the communication, psychology, and counseling departments at their colleges and universities for additional resources appropriate to their specific needs.

Fundamentally, effective communication will facilitate accountable, cooperative, and humanistic care-giving. The following guidelines, adapted from Hamachek (1971), summarize this unit well and reinforce the importance of enhancing self-concept and communication competencies for professionals in all areas of health and education.

1. Understand that we communicate what we **are**, not just what we say. We communicate our own self-concepts far more often that we communicate information.

2. Understand that anything we do or say could significantly change an individual's attitude about himself/herself for better or for worse. We must understand the implications of our role as persons who are important or "significant" to others if we are to utilize that role properly.

3. Understand that individuals behave in terms of what seems to be true, which means many times communication occurs, not according to what the facts are, but according to how they are **perceived.**

4. Be willing to deal with what a message **means** to different people. In the truest sense of the word, we must be willing to deal with the **interpretation** of a subject as we are to deal with the information about it.

5. Understand that we are not likely to get results simply by telling someone he/she is worthy. Rather, we imply it through trust and the establishment of an atmosphere of mutual respect. One good way to start is to take time to **listen** to what others have to say and to use their ideas when possible.

6. Understand that behavior which is distant, cold, and rejecting is far less likely to enhance self-concept or communication than behavior which is warm, accepting, and discriminating.

7. Be willing to be flexible when communicating with others.

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The process of conflict is analyzed and strategies are provided to change conflict situations between individuals or small group members into problem-solving situations. Effects of language, personal behavior, attitudes, and organization on the achievement of communication outcomes are addressed. Emphasizes an inegrative decision-making method of problem solving to resolve conflicts.

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A detailed review of all areas of nonverbal communication with numerous exercises and additional readings. Focuses on the functional nature of nonverbal behavior in all areas of communication, including information transfer, persuasion, and decision-making.

UNIT 4

Issues in Identification

ANTHONY S. BASHIR

UNIT 4: IDENTIFICATION

PURPOSE AND OBJECTIVES

Purpose:

To explore the processes involved in the screening, assessment, planning, and review of educational and health-related services for children and youth with handicapping conditions.

Specific Objectives

At the conclusion of this unit, readers should be able to:

1. Identify the indicators of the handicapping conditions included in Public Law 94-142:
   a. Visual impairments
   b. Hearing impairments
   c. Orthopedic impairments
   d. Speech impairments
   e. Mental retardation
   f. Severe emotional disturbances
   g. Learning disabilities
   h. Other health impairments

2. Identify and monitor "high-risk" children consistent with professional roles.

3. Promote accountable decision-making in the design of early identification and intervention strategies for children and youth exhibiting handicapping conditions.

4. Discuss the roles and responsibilities of all health and education professionals in coordinating identification and screening procedures and non-discriminatory, multidisciplinary assessments of youngsters with disabilities.

5. Recognize when referrals for education and/or health services are inadequate, poorly coordinated, and/or necessary, and describe the presenting problem(s) or concerns(s) to the appropriate referral agencies or qualified professional resources.

UNIT 4

Identifying Children and Youth with Handicapping Conditions: A Guide for Health Professionals

ANTHONY S. BASHIR

The enactment of Public Law 94-142 has influenced and altered the rationale and methods for the identification, assessment, and education of individuals with various kinds of handicapping conditions. As a result, qualified individuals from education, medicine, and psychology, as well as professionals in related health care disciplines now work in close cooperation with each other in determining the status and needs of individuals with handicapping conditions. Multidisciplinary teams are deemed essential for assessment, planning, treatment, and review of programs for these individuals.

Public Law 94-142 decidely has influenced the practice of health professionals. Traditionally, many of these professionals have practiced principally within clinical-medical settings. The law and its regulations, however, have motivated changes in the context of practice to include public and private education settings. Now health professionals are engaged actively within educational settings either directly or through contractual arrangements between agencies. Their roles and responsibilities for screening, identification, assessment, and planning activities are coordinated through multidisciplinary team efforts. Goals of treatment are formulated to meet the needs of individuals within the schools.

As a result, new models of practice are needed. The role of the health practitioner has changed regarding the identification of various handicapping conditions, as well as in referral and advocacy initiatives. To help prepare health professionals for their roles in identifying youngsters with disabilities, this chapter will present some of the requirements of federal law as they address issues related to the use of high-risk criteria, screening systems, and definitions of handicapping conditions.

LEGAL REQUIREMENTS

As described in **Unit 1**, Public Law 94-142 guarantees that all children between the ages of 3 and 21 who have handicapping conditions will be identified and provided a free, appropriate public education. The word "appropriate" is important. Without this assurance, access to a meaningful education frequently would be hampered. An appropriate education requires modifications to and adaptations of a youngster's education program. These accomodations and services are based on an assessment of the child's strengths, abilities, and weaknesses. The results of these assessments, along with data from other sources, provide the basis for the youngster's individual educational programs.

Procedures governing the identification and assessment of disabilities in children are determined by both federal and state policy. In some situations, identification and assessment are separated as two procedures. For the purposes of this unit, however, assessment is considered an integral part of the descriptive process necessary for an appropriate delineation of the needs and related-service requirements of individuals with handicapping conditions and their families.

In Public Law 94-142, evaluation refers to the procedures used to determine whether a child has a handicapping condition and the kinds of special interventions needed as a result. Three major conditions are imposed on all evaluation procedures:

1. **Evaluation must not be racially or culturally discriminatory.** In recent years, Blacks and other minorities have been over-represented in some special education classes. Arguments presented in courts have charged that traditional, standardized intelligence tests were not valid measurements of cognitive abilities when used to assess individuals from minority groups. This was so because the establishment of normative data were based frequently on insufficient numbers of minorities in the standarization samples. Consequently, certain intelligence tests did discriminate against individuals from minority groups. The issues in assessment are serious and complex.

   Most professionals use tests without an awareness of how they were normed or developed. Conscientious professionals now must study the theoretical basis of tests, the characteristics of the population used in the standardization of the tests, and the methods used for establishing the norming data and the validity and reliability of the tests.

   No single test intrument can provide sufficient information on which to base identification or diagnosis. An understanding of the theoretical basis of a test scale as well as its limitations and restraints on interpretation will be essential for health professionals. While not within the scope of this chapter, compendiums of critical reviews on various tests are available (See for example, Burrows, 1978).

2. **Evaluations must be administered in the child's native language or predominant mode of communication unless it is not feasible to do so.** Interpreters must be provided for children whose native language is not English and for those individuals with hearing impairments who use sign or manual systems of communication. This requirement is not always easily met. In some cases, clinics and schools have children from more than 20 different countries or native American tribes, some with several dialects. Every effort must be made to find interpreters for these populations before a "not feasible" decision is made.

   For the health professional, advocacy initiatives will be necessary for the child who is a user of an augmentative communication system. This might be particularly so for the child with severe cerebral palsy. Unable to speak because of significant neuromuscular involvement, this person may respond well to assessment when working within an adaptive manner and through the use of an augmentative system.

3. **No single procedure shall be the sole criterion for determining an appropriate education.** Children may not be placed in special education classes or related service programs on the basis of a single test. Behavior is complex and multidimensional. No single test is capable of providing sufficient information to describe the diversity in behavior or explain its basis. Consequently, those responsible for the assessment of individuals with handicaps will need to rely on the use of a number of measurement instruments in determining the status of the individual. In essence, a multidisciplinary team will need to address the behavioral and psychological complexities of the youngster to determine educational placement.

How do these requirements apply to the health professional in clinical settings? Child eveluations conducted in clinics and hospitals may be used by schools in making decisions about the child's education program. Schools frequently refer individuals to other agencies for evaluations and determination of related-service needs such as medical/neurological status, physical and occupational therapy needs, as well as vision, hearing, speech, and language status. In addition, health professionals may provide "independent evaluations" for parents under Public Law 94-142. An independent evaluation is one conducted by a qualified examiner who is not employed by the public schools. In some instances, an independent evaluation may be requested by the parent as a means of achieving a second opinion. In these instances, the health professional will need to develop communication strategies that will facilitate relations with the family and the educational system.

It is important, therefore, for health professionals to understand federal as well as state and local policy. Several areas of state policy are critical:

- **DEFINITIONS**. Variations exist between federal and state policies regarding the types of disabilities included under the term "children with handicapping conditions" or "children with special needs."
- **ELIGIBILITY CRITERIA.** In order to participate in special education programs and receive related services, children must meet the criteria established by their states. For example, candidates for learning disabilities classes may have to score below the tenth percentile on a certain test in one state and below the fifteenth percentile in another. Some states require general health screening for all disabilities, while others specify general health screening only if a need is indicated.
- **REQUIRED PROCEDURES.** Most states require a battery of tests be administered prior to a determination of need and the implementation of required services and/or therapies. In some cases, states publish a list of approved instruments and specify the number of tests which must be administered to verify a suspected disability.
- **QUALIFICATIONS OF EXAMINERS.** Professionals must meet state education agency certification requirements. When qualifications are not met, the tests administered may not be valid for determination of special education placement purposes.

HIGH-RISK APPROACHES

While identification in this unit applies to children and youth of all ages, there is particular benefit in early identification and intervention. Smith (1980) cites the psychological and prognostic benefits to the child, to the family, and to society. In addition to other implications of early identification, long-term economic issues related to care form another basis for early identification. The first three or four years of life is a period characterized by rapid growth and development. By identifying a youngster's disability and providing the child with services during this early phase of life, there is an increased liklihood of remediating or lessening the effects of the handicap. Postponing intervention, on the other hand, could have negative effects such as the development of an emotional disability or other secondary handicaps, increasing the costs for rehabilitation. These benefits of early identification apply to youngsters "at-risk" as well as to children with identified handicapping conditions (Smith, 1980, pp. 6-12).

Smith (1980) defines "at-risk" children as:

> Children whose medical or environmental circumstances place them in danger of developing a handicapping condition, and is used interchangeably with the term "high-risk." Medically "at-risk" children include those who are premature, have a low birth weight, or who possess a medical condition which has been shown to frequently result in a handicap if not treated at an early stage. Environmental conditions, which have been proven to increase the probability of creating handicapping conditions, include poor nutrition, lack of medical care, abuse or neglect, and economic disadvantage. These "at-risk" factors may be present prior to or after the birth of the child (p. 4).

The historical presence of an antecedant risk factor alerts the health professional that an individual is at-risk for subsequent medical or developmental disorders. A body of research exists that addresses the consequences of different events occurring in the prenatal, natal, or neonatal period. The study of these various events is reasonable because all professionals are involved actively in dealing with prognostic problems and outcomes for individuals who are at-risk. Similarly, all professionals share in the responsibility for prevention of catastrophic outcomes. Indeed, all the activities in early intervention programs are directed toward enhancement or amelioration of outcome behaviors. It is important, however, that planning and treatment for developmental disabilities be based on an understanding of the individual's needs and status. This cannot be achieved when etiology or high-risk categories alone are relied on to identify children at-risk. These latter devices are only first steps in the identification process.

Health professionals need to be aware of the conditions that may indicate the youngster is at-risk of having a disability. The use of high-risk indicators is commonly used professionals to identify the possibility of developmental or medical problems. Such approaches are seen in the work of Tjossem (1976) and Ramey, Trohannis and Hostler (1982). The following three categories of risk factors are proposed:

1. **Established Risk**, including children whose disabilities are related to medical disorders of known cause and with documented expectations for developmental problems; e.g., Downs Syndrome, congenital deafness, and/or blindness;

2. **Environmental Risk**, including children whose life experiences cause them to be at risk for disability if intervention is not instituted; e.g., children with histories of abuse, children with failure to thrive, and chronically ill and hospitalized children; and

3. **Biological Risk**, including those children whose prenatal, perinatal, neonatal, or early development suggest biological insult that singularly or collectively increases the chances for later developmental problems; e.g., prematurity or metabolic disease.

The use of high-risk indicators allow for a first step in determining an individual is at-risk. They do not allow for prediction about what aspects of developmental or medical status will be delayed or disordered. Furthermore, they do not specify the means for screening or identifying those individuals who will need services. In addition, some children with histories of significant neonatal complications may do well in the course of their development, while other individuals without significant indicators may evidence later developmental variations which will require extensive attention for appropriate service delivery.

Another approach to the determination of risk for developmental problems is the use of behavioral indices (Liebergott, et. al., 1983). Screening programs based on this method test for an array of behaviors grouped into areas of performance, including sensory, intellectual, communication, social, and motor abilities. The behaviors assessed seem to serve at least two purposes.

The first use of indices is the determination of the individual's abilities in certain areas of ability on the basis of expectation for age level. One disadvantage of behavioral indices, however, is that in most screening instruments insufficient numbers of items are present at each age level or in any one area of behavior to allow for a complete understanding of an individual's abilities. In addition, some items are subjective and rely on parent-clinician agreement for scoring, for example, whether a child combines sounds or enjoys making noises.

The second use of screening tests is to serve as a first level "sieve," allowing the user to identify a child who will need to be referred to other qualified professionals for further assessment and diagnosis. Eventual referral of a child suspected of having a disability will be necessary before a child is identified as "handicapped" under Public Law 94-142 and, therefore, eligible for the special education and related services guaranteed by the law. Such a referral and evaluation are required even when the assessment is conducted for health rather than for educational purposes.

Without a comprehensive assessment, planning for intervention cannot be achieved effectively. Screening is merely the first step to this determination, and as such, is no replacement for a comprehensive, integrated assessment of the individual. The elements of this assessment must be ascertained by the direct and shared decision-making efforts of a multidisciplinary team who work in cooperation with parents and within the requirements established by law.

Although variations exist in individual states, the identification process usually includes the following steps:

A. **Screening:**

- Initial assessment is conducted.
- High-risk indicators are identified.

B. **Referral:** Referral is made specific to a set of chief complaints or concerns.

- Consent for testing from parent or legal guardian is received.
- Decisions for assessments on the basis of chief complaint or concerns are determined.

C. **Assessment:**

- Clinical-educational needs are determined.
- Additional assessments are conducted as required.

D. **Meeting of the Multidisciplinary Evaluation/IEP Team:**

- Assessment findings are shared.
- Findings are integrated.
- The presence or absence of a handicapping condition is determined.
- The Individualized Education Program (IEP) which specifies services to be delivered is developed by parents and professionals (See Unit 1).

E. **Individualized Education Program (IEP) is Implemented:**

- Services are delivered.

- IEP goals and objectives are monitored.
- Student progress is documented.

F. **Annual Review:**

- The IEP team is reconvened.
- Current clinical-educational needs are determined.
- Appropriateness of the Individualized Education Program and placement is discussed.
- Appropriateness of the Individualized Education Program is reviewed and revised as necessary.

G. **Reevaluation:**

- Reevaluation and assessments must be conducted every three years.

If the child is first identified by a health or human service agency, a representative from that agency should notify the local director of special education who will initiate an assessment of the child to determine the need for special classroom services. The school district should be notified, even if the child is of toddler age, so planning for the child can begin in advance. Many school districts have preschool programs for children with disabilities. Health professionals must assume responsibility for facilitating the orderly transfer of care to other public agencies. **Unit 5** provides details for referral, coordination, and management activities.

ISSUES IN SCREENING AND IDENTIFICATION

The purpose of screening and identification procedures is to separate (a) those youngsters who demonstrate no disability; (b) those who are at-risk and will need systematic follow-up for eventual determination of developmental status; and (c) those who demonstrate clear disabilities and, therefore, need services.

Care must be taken in using screening instruments. Too often the items included in current screening measurements assess discrete skills that may not be related to later developmental achievement. Clinicians must not rely solely on these early behaviors to predict future status. Only tests based on longitudinally-derived information about developmental differences among various groups of individuals will allow resolution of the dilemma.

Other issues, including the need for early identification and the use of high-risk approaches have been addressed previously. These issues and limitations of screening suggest an additional consideration for health practitioners: **CONFIDENTIALITY** during the identification process. Controversy regarding the use of high-risk registeries and the ethical considerations surrounding classification of youngsters with disabilities (discussed in the **Introduction** of this book), as well as the possible discriminatory impact on racial or cultural minority groups, attest to the need for extreme caution. Early tests, based on limited data, can become life-long stigmas for a child. Evaluation procedures therefore, must be perceived as a continuing process, not sporadic, irrevocable events. Caution is necessary both for test administration and for the way test results are interpreted and used.

DEFINITIONS OF HANDICAPPING CONDITIONS

Definitions of handicapping conditions provide a basis for identification, research, and funding efforts. As discussed in the **Introduction**, however, definitions often are used as labels, leading to stereotypical and prejudicial attitudes towards persons with disabilities. Further, definitions attempt to be mutally exclusive. In reality, an individual may demonstrate multiple disabilities, as when such generic functions as intellectual, affective, linguistic, and motor skills are involved simultaneously. Consequently, health professionals need to understand the patterns of behaviors demonstrated by groups of individuals, recognizing that all disability groups are heterogeneous, not homogeneous, in composition and that each individual within a group is unique.

Because definitions are descriptions of collective behaviors, they are of limited value. Definitions do not delineate the mechanism involved in the assessment process or in the planning, design, and implementation of appropriate services. They also do not address the similarities or differences between normal and altered development. Definitions seldom account for differences across subgroups of disabilities. In addition, definitions do not reveal how changes in symptoms, behaviors, and needs occur over the life-time of an individual with special needs. Because of the misinterpretations related to definitions, many theoretical, research, and service-related problems occur and confound an understanding of the handicapping condition and the individual with that condition (Bashir, et. al., 1983).

Recognizing both the need for definitions of disabling conditions and the problems associated with definitions, the following brief outline of handicapping conditions and identification issues is offered. This list is intended as a preliminary outline of concerns that can be detailed further by health professionals in their efforts to develop a more complete understanding of the various conditions.

IDENTIFICATION OF HANDICAPPING CONDITIONS

Handicapping conditions included in Public Law 94-142:

1. Hearing Impairments, including Deafness
2. Mental Retardation
3. Orthopedic Impairments
4. Serious Emotional Disturbances
5. Specific Learning Disabilities
6. Speech Impairments
7. Visual Impairments, including Blindness
8. Other Health Impairments

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1. THE DEAF AND HEARING IMPAIRED

A. Definition:

"Deaf" means a hearing impairment which is so severe that the child's hearing is impaired in processing linquistic information through hearing, with or without amplification. "Hard of hearing" means a hearing impairment, whether permanent or fluctuating which adversely affects a child's educational performance, but which is not included under deaf (Public Law 94-142 Regulations 300.5 (1) and (3)).

B. High-Risk Indicators:

Hearing loss can be congenital or acquired. Familial history is important since hearing loss can have a genetic basis. High-risk indicators include:

- Rubella
- Anoria
- Prematurity
- Rh-incompatibility
- Mumps
- Ototoxic Medications
- Meningitis
- Encephalitis
- Congenital Anomalies
- Cleft Palate
- Prolonged High Fever
- History of Chronic Middle Ear Disease

Behavioral Indices:

- Inconsistent awareness or response to sound or speech
- Social situational concerns: Withdrawn behavior, poor attention, and over-activity
- Difficulty with localizing the source of sound
- Delay in the development of language and speech abilities
- Difficulty attending in group situations with improvement in a one-to-one setting

C. Classification of Hearing Impairments—Issues for Consideration:

- Types (conductive, sensori-neural, mixed)
- Degree
- Age of onset

A **conductive** hearing loss is caused by interference with the normal transmission of sound through the outer and middle ear. Conductive hearing loss may be congenital in the case of microtia/atresia (deformity of the outer ear) or ossicular malformation. More often, conductive hearing loss is acquired, as in the case of wax blockage, tympanic membrane perforation, or middle ear fluid. Conductive losses usually are correctable with medical intervention, but respond well to amplification. A **sensori-neural** hearing loss is caused by inner ear or auditory nerve dysfunction. An individual with sensori-neural hearing loss benefits from hearing aid use to the extent that sound discrimination is preserved. **Mixed** hearing loss is a combination of sensori-neural and conductive types. Management strategies such as those discussed above apply similarly to the care of a mixed hearing loss. Some sensory-neural hearing losses may be progressive. Regardless, careful and routine otologic and audiological follow-up of individuals is essential.

D. Assessment Issues:

Assessment should be conducted by a multidisciplinary team and include, as appropriate and as required by State policy, an otolarynogolgist, audiologist, teacher of the hearing impaired, speech-language pathologist, educational specialist, and a psychologist familiar with the unique problems of individuals with hearing impairments.

E. Issues to Consider in Planning Intervention:

Intervention should include accountable decision-making in the design of programs and strategies. A consideration of the following is essential to the planning of effective intervention for youngsters with hearing impairments.

- Early identification and early programs: Auditory Approaches
- Decision regarding oral or total communication
- Amplification needs
- Speech and language therapy needs
- Implications for learning in school: Program Options and Support Services

- Implications for psychological development
- Implications for life planning involving the family, peers, and other health and education professionals, including vocational and independent-living specialists

2. MENTAL RETARDATION

A. Definition:

"Mentally Retarded" means significantly subaverage general intellectual function, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, which adversely affects a child's educational performance (Public Law 94-142 Regulations 300.5 (4)).

B. High-Risk Indicators:

Mental retardation may be caused by genetic, metabolic, environmental, and pre-natal or postnatal factors. Mental retardation also can result as a consequence of infectious diseases, central nervous system damage, toxic causes, or unspecified cultural-familial factors.

Behavioral Indices:

- Delayed acquisition of motor milestones
- Delayed acquisition of speech and language skills
- Inconsistent patterns in the development of attention skills, eye-hand coordination activities, and language comprehension
- Significant reduction in the comprehension and production of language
- Decreased rate and effectiveness in academic learning

C. Classification of Mental Retardation—Issues for Consideration:

- Range of severity
- Differential Aspects of Deviant Functions, including:
    - Cognitive skills
    - Judgment and reasoning abilities
    - Self-help skills
    - Motor abilities
    - Communication skills
    - Socialization skills
    - Academic learning abilities
    - Family-environment interaction
    - Vocational abilities

D. **Assessment Issues:**

- Assessment areas include psychological, medical, communicative, sensory, motor, education, developmental, and socio-adaptive behavior
- Use of non-discriminatory methods and instruments
- Evidence of three criteria: significant intellectual impairment, manifestation during the developmental period, and impaired adaptive behavior

E. **Issues to Consider in Planning Intervention:**

- Educational program needs
- Least restrictive environment
- Independent living arrangements
- Vocational training needs
- Family needs
- Medical needs

3. ORTHOPEDIC IMPAIRMENTS

A. **Definition:**

"Orthopedically impaired' means a severe orthopedic impairment which adversely affects a child's educational performance. The term includes impairment caused by congenital anamoly (e.g., club foot, absence of some body part, etc.), impairment caused by disease (e.g., poliomyelitis, bone tuberculosis, etc.), and impairments from other causes (e.g., fractures or burns which cause contractures, amputation, cerebral palsy, etc.) (Public Law 94-142 Regulation 300.5 (6)).

B. **High Risk Indicators:**

Orthopedic impairments, recognized as neuromuscular or musculoskeletal impairments, may result from congenital or acquired causes.

Behavioral Indices:

- Delay in developmental milestones for rolling, sitting, or standing and walking activities.
- Lack of independence in self-care activities to include locomotion, activities of daily living (eating, dressing, bathing).

- Loss of muscle activity or increased motor activity (spasticity, paralysis, athetosis).
- Decreased arc of motion in joints.
- Loss of or abnormal configuration of limb or body part.

C. **Classification Considerations:**

- Type of impairment
- Site of involvement
- Age of onset
- Sensory, motor, or sensorimotor disturbance (sensory: lack of sensation palsy; sensorimotor: C-6 quadriplegic)
- Available Voluntary movement
- Involuntary movement
- Available Arc of motion
- Presence or absence of independent functional activities

D. **Assessment Issues:**

There is a need to identify clearly the differences among the disabilities described under the collective term "orthopedically impaired." The areas of functioning such as sensory, intellectual, motor, emotional, and developmental growth are involved differently. For example, a child with clubfoot and a child with a significant non-progressive central nervous system disorder resulting from cerebral palsy will require different assessment techniques and procedures.

The determination of need must be made by a multidisciplinary team in which integration of medical and developmental history and status, psychological and socio-adaptive behavior, and educational assessments occur as appropriate. Those individuals providing assessments should be chosen on the basis of professional training and experiences with individuals evidencing a diverse range of orthopedic conditions. The typical orthopedic assessment team consists of a physical therapist, occupational therapist, developmental therapist, psychologist, educator, and social worker.

E. **Issues to Consider in Planning Intervention:**

- Early Intervention Programs: Determine specific needs

- Integrative, holistic approaches for all orthopedic problems which involve parents along with health and education professionals as "primary" therapists
- Accommodation needs:
    - Physical needs, orthotic and prosthetic appliances
    - Motor planning, training, and facilitation
    - Adaptive equipment and adaptation of equipment
    - Environmental needs, e.g., feeding, grooming, bowel and bladder training
    - Architectural accommodations
    - Augmentative communication systems needs
- Curricular needs and provider models
- Social-vocational needs and appropriate planning
- Planning for disruptions in educational process due to need for medical/surgical intervention
- Family assistance
- Extended health or physical care needs.

4. SERIOUS EMOTIONAL DISTURBANCES

A. Definition:

"Seriously emotionally disturbed" means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree: an inability to learn which cannot be explained by intellectual, sensory, or health factors; and inability to build or maintain satisfactory interpersonal relationships with peers and teachers; inapproporiate types of behaviors or feelings under normal circumstances; a general or pervasive mood of unhappiness or depression; or a tendancy to develop physical symptoms or fears associated with personal or school problems. The term includes children who are schizophrenic. The term does not include children who are socially maladjusted but not emotionally disturbed (Public Law 94-142 Regulation 300.5 (8)).

B. High Risk Indicators:

The etiology of emotional disturbances can be genetic, biochemical, or environmental/interactional.

Behavioral Indices:

- The inability to relate or enter into reciprocal activities
- The deterioration of family relationships
- The inability to establish peer relationships or the deterioration of peer relationships
- Inappropriate or bizarre content of communication
- Behavioral disruption, e.g., significant aggressive behavior, disruption in sleep patterns, regression in bowel and/or bladder control, significant changes in feeding behavior
- Irrational or exaggerated fears
- Periods of unexplained sadness, crying, withdrawal, or lethargy
- Periods of "ritualistic" behaviors, e.g., rocking, washing hands excessively, echolalia
- Inability to tolerate change or alteration of routines
- Excessive use of substances such as drugs or alcohol
- Unexplained physical complaints

C. **Classification of Emotional Disturbances—Issues for Consideration:**

- Severity: As a function of perceived social and interpersonal deviancy and loss of functional independence
- Types: Ranging from chronic anxiety, depression, agression, schizophernia and autism
- Age of onset

D. **Assessment Issues:**

- Establish current levels of functioning; e.g., cognitive, emotional, academic, and social functional levels
- Evaluate the factors that interfere with the person's resolution of conflict
- Determine the appropriate milieu for the individual that will facilitate emotional and cognitive growth

- Areas of assessment may include: medical, psychological, socio-adaptive behavior, and educational development.

E. **Issues to Consider in Planning Intervention:**

- Mileau setting; residential setting; other service models
- Psychiatric/Psychological Therapy
- Needs of the family
- Related health needs
- Educational Placement Options
- Special therapy needs; (e.g., occupational therapy, physical therapy, speech-language pathology)

5. SPECIFIC LEARNING DISABILITIES

A. **Definition:**

"Specific Learning Disabilities" means disorders in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell or to do mathematical calculations. The term includes such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include children who have learning problems which are primarily the result of visual, hearing, or motor handicaps, of mental retardation, or of environmental, cultural, or economic disadvantages (Public Law 94-142 Regulations 300.5 (9)).

B. **High Risk Indicators:**

Learning disabilities can be cogenital or result from anatomical differences of the central nervous system (CNS), neuromaturational delay; neurochemical/metabolic imbalance, severe nutritional deficiency, trauma to the central nervous system, or other acquired causes.

Behavioral Indices—Include a History of the Following Characteristics:

- Inattention, distractibility, impulsivity
- Hyperactivity

- Hypoactivity problems with eye-hand coordination
- Problems in orientation and laterality
- Presence of language disorders
- Perseveration
- Perceptual motor difficulties
- Motor imbalance
- Problems in self-regulation and social interaction

C. Classification of Learning Disabilities: Issues for Consideration:

- Type of presenting disability:
    - Disorders of listening
    - Disorders of oral expression
    - Disorders of written expression
    - Deficits in acquiring basic reading skills
    - Deficits in reading comprehension
    - Deficits in conceptual functioning and meaning
    - Deficits in mathematical calculation
- Severity of presenting disability

D. Assessment Issues:

The goal of assessment is the determination of strength and weakness patterns and learning styles as they relate to the individual's learning disability. Assessment should be conducted by a multidisciplinary team to determine the type of learning disability, describe the educational and related service needs, and facilitate planning and intervention. Team members may include an audiologist, speech-language pathologist, reading specialist, psychologist, occupational therapist, social worker, and the regular classroom teacher.

E. Issues to Consider in Planning Intervention:

- The type of educational program; e.g., regular class with additional services, the use of the resource room, or substantially separate program
- The educational training and experience of educators and related service providers with individuals with learning disabilities
- The coordination of related-service needs to the education of the individual with learning disabilities

- Psychological and counseling needs
- Pre-vocational and vocational planning
- Family needs

6. SPEECH IMPAIRED

A. **Definition:**

"Speech Impaired" means a communication disorder, such as stuttering, impaired articulation, a language impairment, or a voice impairment, which adversely affects a child's educational performance (Public Law 94-142 Regulation 300.5 (10)).

B. **High Risk Indicators:**

Speech impairments may result from structural causes, central or peripheral nervous systems disorders, mislearning; or a sensory, cognitive, emotional, or acquired basis (e.g., stroke-induced).

Behavioral Indices:

- Hearing impairments
- Significant history of chronic middle ear disease in the first two years of life
- Structural disorders of the oral cavity, such as cleft lip and palate
- Neurological disease or disorders
- Lack of two-word phrases by 2 years, 6 months
- Lack of comprehension of name, body parts and common objects by 2 years
- Lack of sentences by 3 years

C. **Classification of Speech Impairments—Issues for Consideration:**

- Types of Disorders

  1. **Resonance Disorders:** Deficits arising from a disruption in normal oronasal sound balance and most commonly heard as hypernasality or hyponasality. Resonance disorders are frequently present in the speech of individuals with palatal deformity; e.g., cleft lip/palate.

2. **Voice Disorders:** Deviations in the quality, pitch, or loudness of the voice. The basis of these deficits may be physiological and/or psychological in nature.

3. **Fluency/Rhythm Disorders:** Disruptions in the natural flow of connected speech. The most common form of the disorder is stuttering.

4. **Articulation Disorders:** Problems in speech sound production, such as substitution of one phoneme for another, distortion of phonemes, and omissions or additions of phonemes. Significant disruption in speech production is seen in some children with cerebral palsy and may necessitate consideration for or use of an augmentative communication system.

5. **Language Disorders:** Disruptions in the person's ability to comprehend and/or use spoken, written, read language. These individuals evidence problems in the use of language for purposes of social dialogue; in addition, the majority of these individuals will evidence academic learning problems.

- Severity

- Age of onset

D. **Assessment Issues:**

Assessment of speech impairments should be conducted by a speech-language pathologist and audiologist. A measure of speech production, an examination of the oral peripheral mechanism, and a measure of language understanding, production, and use should be included at a minimum. A hearing screening is essential. Medical/neurological, psychological, and related-health services also may be required. Referral to other specialists should be made when indicated on the basis of history, examination data, and other presenting complaints or conditions.

E. **Issues to Consider in Planning Intervention:**

- Early intervention programs

- Pre-school and school-based speech improvement/language classes

- Psychological/counseling support systems

- Family support systems

- Medical-surgical intervention
- Frequency and duration of speech-language therapies
- Audiological assessments and management
- Consultation with teachers
- Educational implications; e.g., impact of language disorders on learning to read and write

7. VISUAL IMPAIRMENTS

A. **Definition:**

"Visually Handicapped" means a visual impairment which, after correction, adversely affects a child's educational performance. The term includes both partially-seeing and blind children (Public Law 94-142 Regulation 300.5 (11)).

B. **High Risk Indicators:**

"Visual impairments" may result from infections, injuries, excessive oxygen neonatally, tumors, rubella, or other prenatal and immediate post-natal conditions, or may occur in conjunction with other developmental disabilities. Two categories of behavioral indices occur:

1. **Appearance of the Eyes:**

   - Swollen or red-rimmed eyelids
   - Crusts near the lashes
   - Frequent sties
   - Unusual discharge from the eyes or along the lids
   - Eyes appear to wander when child tries to focus
   - Pupils of the eyes are of different sizes
   - Eyes that involuntarily move constantly
   - Drooping eyelids (ptosis)

2. **Visual Behavior:**

   - Complaints of aches or pains in the eyes, excessive headaches, dizziness or nausea after close eye work

- Squinting, blinking, frowning, facial distortions, constant rubbing of the eyes or attempting to brush away a blur; tilting of the head when seeing; closing or covering one eye when looking or reading
- Undue sensitivity to light
- Holds reading material too close or too far away; frequently changes the distance of reading material from near to far
- Head thrust forward or body tense when viewing distant object
- Inattentiveness during reading; cannot read for long periods without tiring; reads more poorly as time span increases
- Tendencies toward reversals of letters and words or confusion of letters and numbers and similar shapes
- Poor spacing in writing

C. **Classification of Visual Impairments—Issues for Consideration:**

- Site of lesion
- Type of disorder: visual acuity, visual field limitation, progressive eye disease (e.g., glaucoma), physical condition which may lead to gradual vision loss (e.g., diabetes), and binocular vision problems
- Severity of disorder
- General level of functioning
- Age of onset

D. **Assessment Issues:**

Assessment of visual impairments should include medical (including ophthalmological), educational, and psychological evaluation. A family health history may indicate a potential for visual handicaps; for example, prenatal maternal disease. Tests should include visual acuity, physical appearance of the eyes, muscle imbalance, and color vision. Degree of dependence in exploring and dealing with the environment, compensatory methods of discrimination (auditory and tactile), attention span, and blindisms (rocking or shaking of the head), as well as emotional and social adaptation status should also be noted.

E. Issues to Consider in Planning Intervention:

- Medical management, need for surgery or glasses
- Type of educational setting
- Ambulation and parapetic training needs
- Use of special equipment; i.e., records, typewriters, brail imprinters, talking book machines
- Mobility issues; home environment, transportation
- Pre-vocational and vocational aspects
- Personal and social intervention needs

8. OTHER HEALTH IMPAIRMENTS

A. Definition:

"Other Health Impaired" means limited strength, vitality or alertness, due to chronic or acute health problems such as a heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophillia, epilepsy, lead poisoning, leukemia, or diabetes, which adversely affects a child's educational performance. The term also includes children with autism (Public Law 94-142 Regulation 300.5 (7)).

B. High Risk Indicators:

Health impairments are considered handicapping conditions under Public Law 94-142 if, as a result, the child requires special education and related services. The causes of health impairments are too varied to list and may be congenital or acquired. Behavioral indices may include any of the indicators listed for other disabilities.

C. Classification of Health Impairments—Issues for Consideration:

- Type of impairment
- Specification of functional limitations in sensory, motor, intellectual, emotional, stamina, independence, or other areas
- Severity

- Age of onset

- Presenting symptoms, e.g., frequent malseizures

D. **Assessment Issues:**

Assessment must be multidisciplinary and multifactored including appropriate medical, education, socio-adaptive behavior, and psychological components as necessary.

E. **Issues to Consider in Planning Intervention:**

An approach which integrates the unique and differing ways various diseases affect a child's life and consequently his/her availability as a learner must be used. Frequently, there is a need to review a child's status as the disease changes and causes changing consequences in life. The impact of chronic illness and acute episodes must be managed realistically in all aspects of the child's life with family, school, and social relations. Clearly, the emotional consequences on learning and self-regard must be attended to. Particular attention should be given to the need for:

- Alternative settings: hospitals, rehabilitation centers, home-bound instruction

- Adjustments in scheduling to accommodate medical interventions or loss of stamina

- Need for life support or other special equipment

- Related service needs

- Preparation of educational personnel for managing the child and providing assistance to peers in clarifying the child's condition and needs

CONCLUSION

When health professionals interact with clients in their professional capacities, they deal with only one aspect of the individual's life. Dieticians look at the person's nutritional needs; dental hygienists view the person's dental health; and so on. As necessary as these roles are, the result can be like the person who is blind describing an elephant by only experiencing the elephant's trunk. For this reason, health professionals and educators must collaborate in conducting screening and assessments of handicapping conditions in children. The following recommendations from the Boston Conference on Screening (MEIR, 1976b) serve to summarize this unit and to provide a framework for an effective identification program for children with disabilities.

1. Tests and systems for screening and identification are useful primarily in the **referral** of individuals for multidisciplinary assessment and formulation of appropriate intervention and follow-up strategies.

2. All screening programs need to **respect the rights** of individuals and their families. A clear statement of what the results are, how they will be clarified, and the course of assessment need to be specified. This recommendation increases the roles and responsibilities of health professionals to (a) understand the roles of other professionals in health care; (b) develop intra- and interprofessional cooperative relationships; (c) formulate appropriate referrals; and (d) provide appropriate advocacy for persons in their care.

3. All screening programs should be seen as **continuous processes** that survey functions throughout the youngster's development. This is critical to ascertain the possible presence of earlier missed conditions, to account for the emergence of "new" problems as a function of age and functional learning demands, and to allow for the removal of the individual from risk categories when problems are resolved.

4. Screening without appropriate follow-up and intervention is futile.

5. The poor predictive validity of screening instruments in some domains--for example, intellectual or communicative abilities--warrants their careful use.

6. At all points in the identification process, a coordinator or coordinating agency should exist to ensure an integration of screening, referral, assessment, and service delivery activities.

7. Agencies should provide time for staff to update their knowledge and skills regarding identification methods, instruments, and legal requirements via inservice or continuing education programs.

8. Systems for data coordination need to be developed to integrate all the information needed to determine the individual's status and needs at every step in the process--from screening to service delivery.

9. Screening and identification systems serving rural and itinerant populations need to be improved and expanded.

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UNIT 5

Referral, Coordination and Management of Services

JAYN WITTENMYER

UNIT 5: REFERRAL, COORDINATION AND MANAGEMENT OF SERVICES

PURPOSE AND OBJECTIVES

Purpose:

To explore appropriate strategies for referral, coordination, and management of health, education, and related services for youngsters with disabilities.

Specific Objectives:

At the conclusion of this unit, readers should be able to:

1. Identify referral sources within their particular health agency or facility.
2. Identify local, state, regional, and national resources for services for children and youth with handicapping conditions and their families.
3. Identify and use existing networks of community, parent, and disabled consumer groups to assist and support parents and siblings of handicapped children and youth.
4. Use procedures for making referrals for appropriate educational and health-related services, consistent with professional roles.
5. Facilitate and promote cooperation with other health-related and education professionals in providing services to children and youth with disabilities.
6. Identify, use, and promote the use of effective follow-up and case management strategies to facilitate children and youth receiving appropriate services.
7. Facilitate the parents' active involvement throughout the referral process in such a way as to make the best use of their knowledge and expertise.

UNIT 5

Coordinating Services for Youngsters with Disabilities: A Parent's Perspective

JAYN WITTENMYER

In the preceding unit, indicators of handicapping conditions were presented to assist health professionals in identifying children with unique education and related service needs. Once needs are identified, someone must be responsible for linking the child with the services required, often from several agencies. Practitioners in the related health professions may be called upon to assist parents in locating a variety of services or may have direct responsibility for identifying and coordinating such services themselves. Knowing what to do and where to go next is critical to both the child and his/her parents. How and where to refer parents for services for their children, how to cooperate in coordination of services, and the importance of identifying someone to manage the service needs of the child with disabilities take careful consideration and planning.

My role as Amy's mother and case manager for her service needs over the past 18 years has provided me with many insights into the delivery of services. Amy's need for specialized services were identified at birth when she was diagnosed as having Down's Syndrome. Through the years our family has weaved in and out of many services and has had contact with numerous health and education professionals, including psychologists, nurses, social workers, occupational and physical therapists, adaptive physical education personnel, X-ray and laboratory technicians, and others. These experiences have produced both good and bad effects. Luckily, through continued communication between myself, Amy, her two sisters, and her father, we have been able to "weather the storm." In addition, I have worked both as volunteer and paid

> professional advocate to assist other parents, professionals, and the general public in understanding the rights and needs of persons with disabilities.
>
> Much has been said about the need for money to develop services and to train professionals to deliver these services. But if the child and/or family is never referred for those services, then the services do not need to exist.

Decisions regarding referral procedures will be determined, for the most part, by the roles, relationships, and professional responsibilities ascribed to by each of the health and education professions. Despite these differences, knowing what services exist in one's community and how to access them are vitally important roles for all health care and education providers, whether or not they interact directly or consistently with youngsters who have disabilities. Without the additional effort required for coordinating and managing such services, the professional may be creating more problems for the family than he/she solves. Juggling to keep appointments with a variety of specialists, often at some distance from the family's home, finding time to carry out the recommendations of each professional, finding resources with which to pay for treatments, in addition to the daily routine of living and sending the child to school can frustrate and exhaust the most stalwart parent.

These are but a few of the difficulties parents must overcome to obtain comprehensive care for their child. Other barriers include the lack of awareness of handicapping conditions and discrepancies in role definition and delineation among some care providers, causing wasted resources and inappropriate care. Dwindling resources, professional competition, and the lack of interagency coordination result in yet more service delivery inadequacies. In addition, many services simply are not available to be coordinated. When this occurs, the health professional must manipulate systems or parts of existing resources creatively to develop meaningful services for a particular child. Collaboration and cooperation between and among professionals in health and in regular and special education are essential to overcome these barriers.

This unit will help the health professional address these critical issues by presenting suggestions for referral, coordination, and management of services for children and youth with disabilities. Specifically, the reader will learn a parent's perspective on identifying and evaluating potential services and referral agencies, matching the child's needs with appropriate services, using effective referral procedures, and coordinating and managing the delivery of services. Appendix 5A provides a list of federal programs and national organizations concerned with persons with handicapping conditions. These resurces will assist practitioners in identifying locally-available services for youngsters with disabilities and their families.

IDENTIFYING AND EVALUATING SERVICES AND AGENCIES

A good first step in learning the referral process is to understand the process used for referrals in one's own agency and/or organization. It will be important for the health care provider to identify the person in the agency who is the referral contact and to gain an understanding of how referrals come into and go out of the agency. The procedures and forms to be completed should be reviewed and information relating to the agency's responsibilities and procedures for follow-up services should be identified prior to client contact.

Making a Resource File

Once the referral process within one's own agency is understood, the health professional is ready to look at the resources available from the local community, neighboring communities, or state.

There are many ways to begin identifying available resources. At the local level, questioning knowledgeable people in the school system, social services agency, United Way office (if available), and health department, or looking through the yellow pages in the phone book, should provide helpful information about local services for persons with disabilities. The state agencies responsible for public education and/or social services should be contacted for information about services not available locally.

> As a new person in a community, I have found a call to the local or state agencies mentioned above yields additional local and state resources. The more contacts one makes, the more resources one can identify to provide assistance for specific concerns. It takes time, however, to develop contacts and establish working relationships. Time is often a major barrier to providing or obtaining services for persons with handicapping conditions, with parents and care providers becoming frustrated in the process.

Once services are identified, it is helpful to organize them for easy access when trying to match clients' needs with appropriate services. One initial method is to separate the services into two groups: specialized services and general services, using a list or card file system for recording all the services available in each community.

Specialized services are those designed specifically for persons with disabilities and their families. As a result of Public Law 94-142 (discussed in Unit 1), the local school system should be first on the list of specialized services. Educational and related health diagnostic testing is provided by the public schools for all children suspected of having a handicapping condition. Depending on state law and the disability, assessments may be available from birth to 21. If a child is found to have a handicapping condition, the school will provide many, if not all, of the services the child needs. Special educators and related health professionals employed in schools should be helpful in locating other specialized services in the community.

The following is a partial list of potential specialized services. These programs may not exist in every community, particularly in rural areas, and they may be known by other names in some communities. They are listed here to give the health professional some perspective of the broad array of available resources. Additional information on these services is contained in Appendix 5A which is an annotated list of available federal programs of interest to persons with disabilities and their families. These federal programs are offered through local health and human service agencies and should be included when developing the resource file. Local phone numbers for the agencies listed below usually can be found in the Yellow Pages of the telephone directory.

Specialized Service	Where to Get More Information
1. **Regular and Special Education** programs and related health services.	Local school superintendent's office.
2. **Screening Clinics** for hearing and vision.	Local health department; school nurse; or Crippled Children's agency.
3. **Specialized Clinics** for speech-language services, physical therapy, occupational therapy, and services for persons with cerebral palsy, hemophilia, cystic fibrosis and other disabilities.	Local health department; also see listing of disability organizations listed in Appendix 5B.
4. **Special Day Programs** offer a variety of social, daily living, and pre-work skills training.	State or local education agency; vocational/technical center; office of vocational rehabilitation; or organizations listed in Appendix 5B.
5. **Parent Support Groups** for parents of children with handicapping conditions.	Contact one of the organizations listed in Appendix 5B under the specific disability of the child involved.
6. **Sibling Support Groups** for brothers and sisters of individuals with disabilities.	Usually organized under the auspices of a parent group such as the Association for Retarded Citizens (ARC) or other organizations. See Appendix 5B.

7. **Genetic Testing and Counseling** for individuals at risk of having or transmitting genetic disorders.	Local health department
8. **Home Training Programs** for youngsters with disabilities and their families.	Local schools offer homebound instruction for children unable to attend classes; contact community social services agencies to assist families to care for and adjust to children with disabilities.
9. **Specialized Recreation and Leisure Activities.** These range from holiday parties to regular day activities and summer camp experiences.	Community Action Agency if one exists; local Department of Parks and Recreation; or organizations listed in Appendix 5B.
10. **Vocational or Work-readiness Centers** for youth and adults with disabilities.	Local vocational rehabilitation office; school district vocational education director; or organizations listed in Appendix 5B.
11. **Counseling** services for persons with disabilities and their families.	Community mental health center; Crippled Children's Services; or school district psychological services department.
12. **Respite Care** which may include short-term child care, emergency services, and vacation planning assistance.	Local social service agency.
13. **Out-of-Home Living Arrangements** may include boarding homes for children attending special schools, foster care, group homes, half-way houses, specialized nursing homes, and state institutions.	Local education agency; department of social services; mental health, or mental retardation agency.
14. **Information and Referral Services** to assist in identifying available resources and information on how to access them.	Usually a function within each agency and organization. Two national information services are listed in Appendix 5B.
15. **Financial Assistance** to individuals with disabilities and	Local social security office for Old Age, Survivors, and

their families to help meet basic needs.	Disability Insurance (OASDI) and Supplemental Security Income (SSI) programs.
16. **Transportation Programs** for persons with handicapping conditions may include safe and appropriate mass transit, air transportation for individuals, and funds for acquisition and improvement of transportation vehicles, equipment, and facilities.	Airlines will provide information on reduced air fares and other assistance to persons with disabilities and their attendants; contact the state or local department of transportation for other information.

General resources are those available to all members of society, not only to those with handicapping conditions. Occasionally, one hears of a health club or social organization denying membership to persons with disabilities. It is unlawful to discriminate on the basis of a handicap; therefore, persons with disabilities have the right to participate in programs and activities available to the general public. Through their knowledge of general services, the health care professional can assist parents in obtaining support and respite services from the community at large, and increase the quality of life for youngsters with disabilities. The following are examples of general community resources.

General Services	**Where to Get Information**
1. **Medical Care** unrelated to a disability from physicians, dentists, and other medical professionals.	Yellow pages of the telephone directory.
2. **Day Care** for working parents; nursery schools.	Yellow pages; classified advertisements.
3. **Children's educational, social, recreational**, and/or **religious programs**.	YMCA; YWCA; Boy Scouts; Girl Scouts; 4-H Clubs; churches and synagogues.
4. **Single Parent Groups** offer support, information, and social activities.	Yellow pages; churches and synagogues; Parents Without Partners (PWP).
5. **Support for Children** in single parent families.	Big Brother/Big Sister Program.
6. **Family Planning Assistance.**	Public Health Department; Community health clinics; Women's Health Clinics; Family Planning Organizations.

7. **Child Abuse Prevention** and **Treatment.** Handicapping conditions have been both a consequence of and a suspected contributing factor in child abuse and neglect cases.	Local human service agency; health department; or Parents' Anonymous.
8. **Food and Income Assistance** programs such as food stamps, homemaker services, the WIC program (supplemental food program for women, infants, and children) aid to families with dependent children.	Local food stamp office; health department; local public assistance (welfare) agency.
9. **Fundraising, social and service** activities.	Social and fraternal organizations such as Lions; Elks; Shriners; Moose Lodge; Junior League; Business and Professional Women's Clubs; Jaycees; Jaycettes; and the Veterans of Foreign Wars.
10. **Advocacy** and **Legal** assistance.	Public interest law firms; League of Women Voters; state Protection and Advocacy Office (listed in Unit 6).

Agency services are appraised initially to determine their suitability for inclusion in the resource file and potential for meeting the needs of youngsters with disabilities. They also are evaluated over time to insure referrals and service are handled expeditiously and effectively. The initial evaluation generally occurs via a telephone interview or mailed questionnaire, at which time the following information is collected for each entry in the resource file.

- Agency Name
- Address
- Phone Number
- Contact Person
- Office Hours
- Description of Services
- Client Eligibility Criteria
- Referral Procedure
- Fees/Costs

As the resource file is developed and agencies are further assessed, additional information which will be helpful for parents of children with disabilities should be included: Is it best to contact this agency early in the morning or late afternoon? Does one agency work with some disabilities better than other agencies? What should the parents bring with them for their first visit (e.g., birth certificate, insurance card)? Is one contact person more sensitive to families of children with disabilities than another person at that agency? The card file of local resources also should contain information regarding the referral process. Identify the forms, letters, and background information required. What are the agency's follow-up policies and procedures? How much time will it take to receive the service following a referral?

MATCHING THE CHILD AND THE SERVICE

Once the child's needs are assessed (discussed in Unit 4) and the available resources known, the next step is to match the two together. In addition to knowledge of the child and community resources, this step requires good judgment, sensitivity, tact, patience, and persistence.

Not all agencies work well together. Some, though appropriate services are available, refuse to serve children who can not pay for their services. Sometimes the child must meet very narrow eligibility criteria. It is not unusual for agencies to retest children referred to them whose test scores are in the borderline range and to deny services if a child scores a few points higher on the retest. Some children with multiple disabilities will not be eligible for services from an agency equipped to serve only one of the child's needs. A frequent example is a child with psycho-social problems in addition to another disability. One agency may treat this child as though the emotional problems were primary and not within the scope of its services, rather than coordinate services with another agency that would handle the psycho-social needs. Professionals must know the challenges that await them if they are to facilitate the delivery of appropriate services to children with handicapping conditions.

The general and specialized resources listed earlier contain suggestions, such as local or state funding sources, which may help in creating new services to meet the unique needs of a particular child. This is necessary particularly when no match can be made between the child and currently available services. In addition, for rare handicapping conditions, services are regionalized and parents may need to travel out of state to obtain treatment for their child.

Unfortunately, no quick formula or easy solution for matching children and services exists. The best preparation for this step is to find out as much as possible about one's community and state services and to carefully review the child's diagnostic records before attempting to make a referral. Carefully summarizing the reasons for the referral will help the intake worker at the referral agency determine if indeed a match is made.

Working with the parents through a systematic problem-solving process should help in making referral decisions. Thus, the needs of the youngster must be clearly identified and defined, resources systematically reviewed and analyzed, and criteria determined for the best solution. Comparisons are made for costs, eligibility requirements, distance from home, and so on, until a proper fit is assured. Sometimes a phone call to verify some detail can save parents a wasted trip.

The following case study illustrates the process of matching the child's needs with appropriate services. In this example, the child, Mary, is eight years old and has mild cerebral palsy. She is moderately retarded, moderately overweight, and has controlled seizures and asthma. She lives at home with both parents and attends a special education class. Mary's parents are devoted to her but after eight years of constant searching for medical, social, and educational services and maintaining their daughter on a limited income, they both feel frustrated and exhausted by their efforts. The service needs identified by the care provider and with Mary's parents are listed below with the agencies most likely to meet the needs.

Services Needed	**Refer to**
Family Support Program	Association for Retarded Citizens
Weight Control	Dietitian/Health Dept.
Case Manager to Coordinate School and Social Services	Medical Assistant/Parent/ Special Education Teacher
Respite Care	24 Hour Residential Program/Mental Health Agency/ Title XV Social Services Agency
Dental Care for Seizure Victims	Dental Hygienist
Training in Walking, Sitting, Motor Skills	PT, OT/Crippled Children's Services

Once service needs and potential referrals have been identified, the health professional, in concert with the parents, should determine a course of action and identify the next steps, including timelines and the person(s) responsible for implementing each action. In Mary's case, parents and professionals should continue the problem-solving process in deciding whether the parents or a professional should initiate the referrals required, conduct the necessary follow-up, and monitor services as Mary's care manager.

The following section discusses types of referral and responsibilities of each party in the referral process.

USING REFERRAL PROCEDURES

Types of Referral

As noted earlier, the roles, relationships, and professional responsibilities of the health care provider will determine general referral activities and procedures. Further decisions will concern the type of referral provided--direct or indirect. With the **indirect referral process**, information on available services is provided to the parents and the responsibility falls on the parents' shoulders to make the referral contact and follow through. Discussing the types of services available in the community with parents is one example of an indirect referral. The parents would then be responsible for seeking out the telephone number and address of the service they are interested in and for making their own contact. Providing the parents with the name and telephone number of a specific service also would be considered an indirect referral. The parents then would take the responsibility for contacting the referral source and for following up when necessary.

Indirect referral is used primarily for two reasons. First, when the parents have assumed the case coordination or management of their child's services, they may only want ideas of available resources for services in their community. The parents then select the resource they wish to call. The other reason for indirect referral is if the health professional is relating to the family as a neighbor or friend and does not want to get too involved in the process. Sometimes indirect referral information is provided to let the parent know that services are available and that they, the parents, are not alone in seeking services for the child.

The **direct referral** is a process in which both the parent and the health professional take responsibility for the referral contact and follow-up. Methods of referral include telephone, written requests, and personal contacts.

One method of direct referral is when the health professional makes a telephone referral on behalf of the parents who have a child with a disability. This call may be made to an agency or organization providing either a general service or a specialized service and may be directed to a personal friend or trusted colleague of the health professional. With this approach, the health care provider generally makes the first appointment for the parents. A direct referral also may take the form of a written letter or standardized form. After receiving a written referral, the referral agency can then either contact the health professional or the parents to make the first appointment. A written referral also may follow a telephone contact to satisfy agency policy, to provide additional data, or to fulfill the request of the referral contact.

Whether the child is referred by telephone or letter, it is important to provide a description of the referral reason so that no time is lost in delivering services. Results of tests, observed behavior, and professional concerns should be shared during the referral process. Name, address, and phone number should be included so the referral agent can contact the health professional for further information. A sample referral form may be found in Appendix 5C.

Also, it is important to determine the information needed from the parents and child. How is the referral agency going to use this information? How useful will the information be to the service needs of the child or the parent? For instance, the health care provider should not ask about the sex life of the parents prior to the child's birth unless the relationship of how that information is relevant to the child's present service needs can be illustrated. Respect the parents' right to privacy.

The last point to remember in providing information about youngsters with handicapping conditions is confidentiality. Remember to obtain the parents' permission to share information about their child. Store test data and other information in a safe place and do not release it to anyone without the parents' permission. (See Appendix 5D for a sample release form.)

Now that the decision is made to refer the parent and/or the child, there are other considerations which must be decided: Who is going to take the child to the referral agency--the parent alone, the health professional alone, or both the parent and professional? Does the parent have transportation available? Is there a need for babysitters for other children in the family? Should the referral agency meet the family in the family's home, in the referral agency's office, or in the office of the health professional who is making the referral? Should both parents, if available, be present at the first appointment with the referral agency? What do the parents need to bring with them for the first appointment? Are there special instructions the child must follow prior to the referral visit (such as abstaining from solid food for several hours, bringing a urine sample, current medications or special adaptive devices)?

Points to Remember:

When making referrals, do remember to:

- Provide reason(s) for referral;
- Include all relevant data;
- Respect parents' right to privacy;
- Maintain confidentiality of records; and
- Help parents prepare for the appointment.

PARENTS' ROLE

Just as in the identification and assessment phases, parents should be involved throughout the referral and coordination of service processes. Health professionals who work with parents in defining the youngster's needs help insure both comprehensive solutions and collaboration in the remediation stages. The health professional should help parents understand what services their children may need, where these services are available, and how parents may obtain these services for their children. One aspect of the health professional's responsibility in helping the parent understand the process is to "listen" to what the parents say. As noted in **Unit 3**, through active listening, the health care provider can determine whether parents have understood the explanation of the service(s) needed or whether the parents require more information or support concerning the referral process.

It is not easy for parents to be told they have a child with special educational, medical, or social needs. It takes time for parents to absorb this information, understand what it means for their child, and then make the best decision for their child. **Unit 3** on Communication provides general strategies for interacting with clients and their families. There are, however, some additional helpful hints to remember when working with parents during the referral and management of services for their child.

- Emphasis should be placed on discovering the child's accomplishments and the parent's successful strategies, not only on identifying unmet needs. When interacting with parents, therefore, it is preferable for the professional to ask questions and listen carefully in a problem solving approach rather than simply to give directions or solutions to parents. Parents have valuable data which can be used in addressing their child's needs and should be considered part of the team with the professional. Through collaboration with professionals in a problem-solving approach, parents increase their self-confidence and accept themselves as part of the solution instead of of as part of the problem, enhancing their abilities to function as their child's own case managers.

- A parent may refuse another referral agency recommended by the health professional because of a previous bad experience with a referral agency. The professional needs to understand the history of the situation--needs to understand the parents' previous experiences--before attempting a new referral which may be the parents' tenth such referral in as many months.

- Also, the professional should be alert to the parent who is "shopping around" from referral to referral trying to find a "cure" for their child. Instead of another professional's diagnosis or treatment, this parent may need a parent-to-parent referral. Another parent may be able to "get through," whereas the health or other professional may have failed.

- And lastly, a health care provider must remember that he/she sees the child for a limited period of time, while the parent has responsibility for the child for the entire twenty-four hour day. The behavior or potential problem perceived during the short visit spent with the child and/or parent may be caused by something that happened earlier in the day and may not be a true reflection of the child's condition or needs. Also, in unfamiliar surroundings a child may act or react quite differently than when in familiar surroundings such as his/her home.

FOLLOW UP ON REFERRAL

Following up on a referral is as important as making the referral itself. Follow-up takes different forms. One way is for parents to assume the responsibility for contacting the professional after the referral. The parents may want to thank the health professional for guiding the family in the best direction for their child or to express their negative reaction to the referral staff or service recommended. Sometimes parents will seek clarification and/or understanding of what they heard from the referral source or they may just want to talk about their child and his/her service needs. Maybe the parents want another referral source.

If parents do not take the responsibility for providing feedback regarding their experiences, then the referrer should assume the responsibility for follow-up. The health care provider should first check with the referral agency to determine if additional information is needed and to determine the referral outcome from the agency's point of view.

Next, the referrer should contact one or both parents. If the parents did not keep the appointment, discuss what can be done to assist them in rescheduling. There may have been legitimate reasons why the appointment was missed. Assist the parents in sorting the issues to ensure the child receives the services he/she needs. If the parents kept the appointment with the referral agency, discuss with them their reactions, additional concerns, and further assistance needed.

Professionals who make frequent referrals may find it helpful to maintain an agency referral follow-up log to help monitor service delivery and effectiveness. The most helpful logs contain the following information:

- client's name
- referral agency
- contact person
- referral method (phone or letter)
- service and date requested
- date of initial contact
- date of service delivery
- comments on quality of the service

A two-step referral and follow-up log can be found in Appendix 5E. A quick glance at such a log will reveal delays in service delivery, as well as aid in case management and agency evaluation. When delays are noted, a phone call is in order to determine the cause of the delay and to assist, if possible, with any problem uncovered.

To obtain the date the initial contact or intake appointment occured, the date service delivery began, and comments on the quality or effectiveness of services, health practitioners need to check back with referral contacts and parents. Including an agency response form at the time of referral can save those making referrals from repeatedly calling agencies to follow-up on a referral (See Appendix 5F). If the response form is not returned within two weeks, a second referral, or trouble-shooting call, may be required to achieve results. Monitoring referrals in this way often reduces delays in service delivery to an acceptable minimum.

COORDINATION AND MANAGEMENT OF SERVICES

Just as in the referral process, health practitioners must work closely with parents through a systematic problem-solving process in coordinating the child's case. In order for the delivery system to work on behalf of children with disabilities and their parents, there also must be coordination of services among the health and education professionals. One person must assume the role of case manager to insure each service is and continues to be appropriate for the child's needs and that additional services are added as needed.

The professional providing physical therapy, for example, also should understand how such interventions affect someone else's role, whether it be the special education teacher, speech-language pathologist, dietitian, occupational therapist, or regular education teacher. Consider the child's confusion when learning to identify common household objects when the teacher uses the term "couch" to identify an object, the speech-language pathologist uses the word "divan" for the same object, and the parents use the word "sofa." This confusion can be corrected easily by coordination and communication among providers, parents, and the child.

Many parents have assumed the role of manager for their child's service needs. This may be the most desirable and appropriate role for the parent. However, this does not let the health or educational professional off the hook from assuming any responsibility for coordination. Team work is needed throughout the child's growth and development to assure the child's needs are met appropriately.

> To assist in this coordination, our family used a "traveling" notebook. Amy carried a note book to school so that her teacher, language specialist, physical therapist, adaptive physical education teacher, and I could all write notes on relevant activities concerning Amy. Each person could read the others' comments and this assisted all involved and saved time by not having to repeat the same activities or concerns.

Another aspect of coordination relates to setting realistic expectations for the child and the family. Without coordination among health and education professionals, activities prescribed may be working at cross purposes. Even more unrealistic is expecting the parent to "program" their child for more hours than the day allows in order to meet the requirements of numerous professionals. This happens more frequently than health care providers recognize. The following example from my own experience illustrates this point.

> When Amy was fifteen and in a Milwaukee Brace for scioliosis, the physical therapist designed a program which required three sessions of forty-five minutes each. This was concurrent with the teacher's program design of two hours a day, plus the mobility and speech teachers' design of another two hours. All of this was in addition to Amy's eight-hour school day. As Amy's case coordinator, I called a meeting to discuss the demands placed on Amy and her family and reorganized her program, so we could have some time just to be a family. Many of the teachers' programs on time and money identification were worked into the regular routine of the day, rather than providing specific set-aside times to work on these concepts. Similarly, Amy's program for improving number and counting concepts were included during the exercises designated by the physical therapist.

Many parents have assumed the role of coordinator or manager on behalf of their child because they (the parents) are the only ones who know all the professionals relating to the child. This frequently happens if the medical, related health, and education professionals are located in different facilities or towns as in the case of some rural areas.

Many factors may be involved in deciding which health professional can or should take the role of case coordinator for the child, when parents are unable or unwilling to manage services for their youngsters. The amount of time required to be coordinator is certainly a determining factor. Other considerations may be mileage and location of professionals and parents (such as in rural communities), or support or lack of support by some professionals on the team. All professionals, whether or not they assume a case management function should take the responsibility of finding out what other services the child receives and determining what coordination would be appropriate under the circumstances.

Professionals and parents working together on behalf of a child with disabilities have been described as the "glue" that really makes the system work. This always is easier to write on paper than it is to put into practice. Most people believe in coordination until someone wants to coordinate **them**. Professionalism, turf issues, personalities, and reimbursement policies all seem to be excuses which prevent services from being coordinated and provided in the best possible way for the child and/or the family.

SUMMARY AND CONCLUSION

This unit has highlighted the referral process with helpful hints along the way. The role of parents has been discussed with key questions to consider in this area. The issues of follow-up to referral have been explored. Not surprisingly, the real key to referral, coordination, and management of services for children with disabilities and their families is **COMMUNICATION**--with the child, with the family, and with the child's other health and education service providers.

> One thing I learned from working with professionals over the years is that we all are able to learn from each other, if we all learn to listen and communicate. The one complaint I hear most from other parents, family members, and persons with handicapping conditions is that the professional didn't listen, didn't appear to hear what parents wanted for their children.

Health professionals play a vital role in the referral and coordination of services to youngsters with disabilities. Their caring and knowledge can help make this a better world for these youngsters and their families.

ADDITIONAL READINGS

Check List of Income Tax Deductibles for Medical Expenses. 1980. United Cerebral Palsy Association, Inc. Pamphlet. Free.

A helpful resource to share with parents.

Monograph No. 4 - The Need for Collaboration Between Educational and Health Services in Programming For Young Handicapped Children. 1977, Margaret Jones, M.D. and T. Berry Brazelton, M.D. United Cerebral Palsy Associations, Inc. 42 pp. Price $1.25.

Reviews the findings of a study of a sampling of seven infant centers located in the East, Midwest and Far West.

Psychological Consultation: Helping Teachers Meet Special Needs. Clyde A. Parker, Editor. 1975. The Council for Exceptional Children. 270 pp. Price $10.00, members $8.50.

Services and practices which help special and regular teachers, principals, and support professionals work together in mainstreaming exceptional children.

Rural Resources. 1980. United Cerebral Palsy Associations, Inc. 15 pp. Free.

A listing of rural organizations and agencies across the nation of interest to persons with developmental disabilities.

Special Education and Pediatrics: A New Relationship. A special issue of Exceptional Children. Jan. 1982. The Council for Exceptional Children. 96 pp. Price $5.00, members $4.25.

A collection of articles discussing the role of the pediatrician in collaborating with education and related service providers.

Guide to Community Awarenes and Interagency Cooperation. 1981, Jacquelyn O. Jones, Kathleen Petisi, Carol S. Eagen, and Amy L. Toole. Board of Cooperative Educational Services. 119 pp. Free.

This guide explains methods for helping professionals understand a community's "character" and develop a tailor-made awareness program. It also explains the transdisciplinary team approach to providing a range of services and methods that can be used to encourage attitudes of sharing and teamwork.

UNIT 6

Advocacy

ETHAN B. ELLIS

UNIT 6: ADVOCACY

PURPOSE AND OBJECTIVES

Purpose:

To clarify the advocacy needs of children and youth with handicapping conditions and the diverse roles health professionals may assume in the advocacy process.

Specific Objectibves:

At the conclusion of this unit, readers should be able to:

1. Identify and promote the advocacy needs of children and youth with handicaps.
2. Discuss the concept of "advocacy" and promote an advocacy role for professionals in health.
3. Describe the different models of advocacy and their appropriate use by health professionals.
4. Identify existing or potential coalitions and independent groups with whom to effectively advocate on behalf of children and youth with disabilities.
5. Identify and utilize resources for effective advocacy appropriately.
6. Identify barriers to and solutions for effective advocacy.

UNIT 6

Effective Advocacy: Roles and Strategies for Health Professionals

ETHAN B. ELLIS

Most children are expected to grow into independent adults who are able to survive, even flourish, in the competitive world of contemporary American society. Over the centuries, the family, school, church, and other social institutions have evolved as mechanisms to provide the support, protection, and education those children need to accomplish the growth expected of them.

Until recently, society had quite different expectations of children with disabilities. If they lived at all, and their disabilities were severe, they were expected to be perpetually dependent on their families or to subsist in residential facilities where their basic needs were barely attended to. Those who were blind or deaf were expected to live in their own subcultures on the fringes of society and to interact with that larger society in very limited ways. The meager social resources devoted to those children reflected and reinforced society's meager expectations of them.

Even less focused expectations were formulated for children with less severe, or hidden disabilities. These children were expected to compete with their peers. Why they failed at school or at work, the reasons for their failure were seldom noticed. On the rare occasions when they succeeded sensationally, society applauded their success as an exception.

During the last four decades, some of us have shifted our expectations of children with disabilities markedly. Advances in medicine, health care, and education have enabled many more of such children to become productive adults. Our changing views on the rights of other minority groups have made us rethink our attitudes toward persons with disabilities.

As a result, we have begun to build new social institutions and modify old ones to provide these youngsters the protection, support, and education they need to become independent adults who can function effectively in our competitive society. We have created these changes in our social institutions self-consciously through litigation and legislation. Lawmakers and courts have established the rights of these children to a free and appropriate education. Discrimination against them on the basis of their disabilities has been prohibited. Some of the physical barriers blocking their access to and travel within the larger society have been removed. Programs in education and human services designed to support and protect these children have been created.

These new social institutions which establish the rights of children with disabilities to appropriate education and which provide them with that education have been imposed rather abruptly on the older social institutions through which this society educates its children who are not disabled. While the social institutions of regular education have evolved over time and out of a long tradition, the newer ones requiring that children with disabilities be educated were developed externally by judges, lawyers, and legislators. In many instances, this has led to conflict. Some of those who know, support, and owe their livelihood to the existing institutions have resisted the changes necessary to accomodate children with disabilities. They have also resisted the intrusion of the special educator and allied health professional.

As a result, the health care professional and special educator have had to become advocates for programs which promote the ability of youngsters with handicapping conditions to become independent adults. To do so effectively, service providers must acknowledge the ability of these children. Some reexamination of what is believed about children with disabilities may be required, for those beliefs will determine how health and education professionals provide these youngsters with services as well as how they advocate on their behalf.

This unit will examine how the beliefs and attitudes of those who provide education and health care to children with disabilities affect those services and shape the children who receive them as well as how those attitudes determine the advocacy roles professionals assume on behalf of youngsters with disabilities.

ATTITUDES AND SERVICE DELIVERY

What each of us accomplishes in life is determined to a great extent by what we believe about ourselves and our abilities. These beliefs, in turn, are determined largely by those around us, particularly those who play significant roles in our lives.

As previously discussed in the Unit on Communication, children with disabilities begin life at a disadvantage. Not only do their disabilities objectively limit their accomplishments in some areas, but those disabilities encourage others to view them as being incapable in all areas. This view of others about the limited abilities of youngsters with handicaps often limits their accomplishments more severely than do the physical or mental limitations of the disabilities themselves.

Educators and health care professionals who serve youngsters with disabilities play a critical role in determining what they think about themselves and their ability to become independent, productive adults. They work with those children as they attempt to overcome the effects of those disabilities and develop lifestyles which will accommodate them. While parents and peers also play a part, the perceptions and attitudes of teachers, clinicians, and therapists can make the difference in whether the child with a disability views him/herself as a success or as a failure. This view often becomes a self-fulfilling prophecy.

Even more critically, the professional's view of the child with a disability determines how he or she serves that child and the benefits that child gets from that service. Within reasonable limits, the teacher who believes that the child can learn produces learning children; the speech-language pathologist who believes that the child can talk produces a talking child. When thus encouraged, the child who talks and learns when others thought he could not, goes on to accomplish other wonders thought impossible.

We know little about this magic circle in which belief illuminates teaching and health care so that they in turn beget self-belief and accomplishment in youngsters with handicapping conditions. While we don't know enough about why or how it works, we do know that it works. We also know that it has produced thousands of adults with disabilities that exceeded our earlier expectations of them and helped us to increase our expectations of those who came after them. (Unit 3 discusses some strategies that do increase the opportunities for the magic circle to work in the delivery of services).

This magic circle of belief not only illuminates the delivery of service, it also illuminates and expands the role that professionals assume as advocates for youngsters with disabilities. If a teacher believes that a child can learn, he or she is energized to remove obstacles which block the child from a productive life. If the physical therapist believes that a child can walk or learn to manipulate its environment to its own ends, he/she becomes impatient with the barriers society puts in the way of that child as he/she seeks a greater degree of independence.

That belief and that impatience generate the energy of which creative, effective advocacy is born. Such advocacy may take many forms, dictated by the particular needs of a child or group of children, by the skills of the professional, and by the resources at his or her disposal. Some are obvious, some less so.

THE HEALTH CARE PROFESSIONAL AND EDUCATOR AS ADVOCATES

The following situations illustrate how the health professional and educator can act as advocates for children with disabilities. They suggest ways in which professionals can expand their own advocacy activities.

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As an occupational therapist at a rehabilitation center, Maggie evaluates children with neurological impairments. As an expert witness, she frequently gives evidence supporting the need for related services in due process hearings which are held to resolve disputes between parents and school districts on such matters. She often addresses parent groups on new developments in the treatment of neurological disorders in children. When the parents of her young clients encounter difficulty in coping with their children's disabilities, she encourages them to join parent support groups and arranges for a member to take them to their first meeting.

Maggie is an advocate for children with disabilities when she acts as an expert witness on their behalf. She expands that advocacy role as a lecturer and referral source for parent self-help groups.

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Susan is a dental technician with a large dental group practice. Her sister's son has multiple disabilities which has made her aware of the need for specialized dental equipment for such children. She persuaded her dental group to purchase such equipment. The practice is now recognized as the major source of dental care for children with disabilities in her community. Because of this expertise, they have contracts to provide dental care to the disabled clients of several rehabilitation facilities and health care agencies. Susan's employers have asked her to screen all the patients in their general practice who have disabilities to determine if they are aware of the community services available to them.

Susan's advocacy on behalf of her sister's son has led her employers to become an important link in the network of services to persons with disabilities in her community. It also has increased their business considerably.

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Bob teaches a class of children with moderate mental retardation. He also is president of his district's teachers' association and active in their state organization. When it appeared that the federal regulations implementing the Education for All Handicapped Children Act might be weakened, he persuaded the state teachers association to support legislation which strengthened the state's special education statute.

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Maryanne is a lab technician at a pediatric hospital. Many of its patients attended a private school for children with severe, low incidence disabilities. Maryanne also is active in county politics and hosts teas for candidates during the elections for county supervisors. When the private school had to close because of financial problems, she took an interest and invited several of the parents to discuss their children's future with three of the candidates who were later elected. Within the year, the county built and began to operate an expanded day school for children with severe, low-incidence disabilities.

CHARACTERISTICS OF EFFECTIVE ADVOCACY

These examples illustrate several characteristics of effective advocacy as practiced by health care professionals and educators on behalf of children with disabilities. A closer look will reveal issues related to one's professionalism--both technical and ethical competence as a professional.

One may advocate on behalf of individual children as Maggie does when she gives supportive testimony at special education hearings. One may also advocate on behalf of a group of children with disabilities. That group varies in size according to the level at which decisions are made which affect those children. Susan potentially improved the entire service delivery system for persons with disabilities in her community. Maryanne's advocacy guaranteed services to a narrow range of children throughout her county and Bob's actions improved the educational opportunities of youngsters with handicapping conditions across his state.

A wide variety of skills come into play in effective advocacy. Some skills are job-related, others are not. Maggie uses her professional skills as an expert witness and lecturer and when she makes referrals to parent groups. Maryanne's job brought her in contact with the children who needed a new school but the political skills which made the new school happen were not part of her job description. Bob's familiarity with the educational needs of children with disabilities is rooted in his professional training and experience and he combined it effectively with his position and power in the teachers' association.

Effective advocacy often requires marshalling variety of resources to deal with a problem. We all have or know of resources within our networks that can be brought to bear on the problem at hand. The creativity involved in effective advocacy is to recognize what these resources are and how and when to use them.

The way in which a particular problem is resolved depends on the resources available. Take away Maryanne's political contacts and the children in her county would have been educated by their local districts or sent out of the county to residential placements. Her skills resulted in a different solution and one which the parents liked better. That may be why they sought her out. Take away Bob's position in the teachers' association and the special education laws in his state might have been strengthened by the lobbying of parents of children with disabilities or through litigation. Bob used his position to make the best of several solutions happen.

Finally, each of these advocates went beyond the limits of their professions as traditionally defined to advocate on behalf of youngsters with handicapping conditions. This suggests that those traditional definitions are expanding to include advocacy--advocacy which is necessary if children with disabilities are to live more independently in our society.

Professionals in health and education function in a variety of contexts, relationships, and institutional structures. At times, they may face ethical dilemmas in their roles as advocates. Each situation will evoke different ethical dilemmas, with each demanding decisions which are often in conflict with one another. The ability of the professional to provide competent, yet personalized, humane care, therefore, requires not only technical expertise, but also a clear understanding of one's professional, ethical, and moral responsibilities to clients and other care providers.

Albert Schweitzer defined ethics as "the name we give to our concern for good behavior. We feel an obligation to consider not only our own personal well-being, but also that of others and of human society as a whole" (American Viewpoint, 1980). Viewed in this light, ethical behavior and advocacy go hand in hand. The challenge for professionals is to develop appropriate advocacy behaviors in the context of such dilemmas, including ethical judgment, knowledge of one's rights and responsibilities, accountable and systematic decision-making, and a sensitive and caring interpersonal style.

As advocates for youngsters with disabilities and their families, professionals should be guided by several basic principles. The principles and resources which follow apply for all forms of effective advocacy--for all advocates, whether in health care or education.

PRINCIPLES OF EFFECTIVE ADVOCACY

Advocacy is a very pragmatic business, despite its very principled goals. In fact, its first rule is that problems and resources determine solutions. Despite that pragmatism, there are some basic principles which have proven effective over time. They include the following:

1. **Find out how decisions are made within the system and who makes them.**

   In some decision-making systems, the process is simple and straightforward and the decision-makers are easily identified. In most, however, there are informal processes which are not apparent or accessible to the public. This is particularly true of political decisions but it also is true of educational and health care decisions. It is a popular cliche that many school board budgets are finalized on the golf course. It is equally true that the Individualized Education Programs (IEPs) in a particular school district may be shaped by a dominant member of the child study team exerting influence beyond his/her area of expertise. If you want to influence such decisions on behalf of youngsters with disabilities, find out who makes them and how they are made.

2. **Know as much as you can about decision-makers and what makes them tick.**

   This is a corollary of the first principle, but a very important one. Many positive decisions for youngsters with handicapping conditions have been made by public figures who were very private about the members of their families who had disabilities. Many other such decisions have been made as political trade-offs or to please an actor not apparently on the scene. For example, an influential state senator once persuaded a governor to force two cabinet officers to reach an agreement by threatening to hold up an appropriations bill. He did so when the woman who hosted his campaign breakfasts learned that the lack of agreement was blocking the establishment of day care centers throughout the state. Her advocacy caused $39 million to flow.

3. **Treat each advocacy effort as a unique event.**

   Because Johnny and Jimmy are both fifth graders with learning disabilities, it does not follow that they need the same reading program or that their teacher will be equally interested in the progress of both. Because two school districts voted down the budget for special education, it does not follow that the same strategy will get that budget restored. One district may succumb to a public outcry from the parents of children with disabilities; in another, parents and other advocates may have to elect their own candidates to the school board.

4. **Don't assume that anybody knows anything, but never treat them as if they don't.**

Public officials have to make decisions on many issues and they cannot be informed on all of them. One of the simplest ways to influence their decisions is to provide them with information which is both reliable and favorable to your cause. Do it gracefully and responsibly and they will come to rely on your opinion as well as on your information.

5. **Involve the child with a disability and his or her parents in the decisions for which you advocate.**

The youngster and the family have to live with the consequences of the decisions made; you don't. They have a right to know what you are advocating on their behalf and what impact the outcomes may have on their lives. They also play a part in achieving the objective you both agree to; if they don't understand the objectives or have doubts about them, they will play that role less effectively.

6. **Parents have a right to be wrong . . . within very broad limits.**

Another corollary and a very difficult one: parents have a total picture of their child which is more comprehensive than any single professional has of the child. This often leads to disputes between parent and advocate over what is best for that child. The advocate brings information and analysis to the advocacy situation; the parent brings knowledge of and feelings about the child. If agreement cannot be reached after differences are explored and shared fully, it is often best to be guided by the parents and use the situation as one in which they learn to become more effective advocates for the child.

On rare occasions, parents may be so wrong that what they propose will be obviously and actively harmful to their child. In those cases, the advocate may have to oppose them. That is a critical and heart-rending decision because it threatens to destroy their capacity and confidence in advocating for their child in other situations. It is wise not to make such a decision without consulting a colleague who is wiser and more detached from the situation than you are.

7. **Know your limits.**

    If the child you are advocating for needs a lawyer or other professional advocate, see that the parents get one; don't try to be one. Don't let your role as an advocate conflict with your role as a professional. If that happens on your job, identify an outside advocate for the child. If it happens repeatedly, back up to determine if some of the other principles you have learned here can be applied to change the situation.

RESOURCES FOR EFFECTIVE ADVOCACY

The advocate for children with disabilities must draw upon a variety of resources depending on the problem being confronted and the strategy employed to deal with it. This section identifies some of those more common resource needs. It also describes ways of meeting them.

Laws and Regulations - Federal and State

The rights of children with disabilities are spelled out in a variety of legal documents, federal and state statutes and the administrative regulations implementing them, as well as the decisions of the courts in the federal and state judicial systems. Some of these legal documents require interpretation by competent attorneys, while others are readily accessible to any citizen. The following reviews where they can be found, how to use them, and where to get legal assistance when their interpretation is beyond professional training.

County courthouses and libraries as well as most larger municipal libraries have law libraries which contain printed copies of all the federal and state statutes. They also have copies of the codes or regulations promulgated by the federal and state agencies responsible for administrating laws. While the statutes may require legal interpretation, the administrative codes or regulations are written so that nonlawyers can use them in their daily work. With a little patience, the average citizen can master them. Most libraries have staff who can lead one to them.

The pivotal statute in the area of rights for children with disabilities is Public Law 94-142, the Education for All Handicapped Children Act. (See Unit 1 for a discussion of the history and provisions of this federal law.) Its provisions are spelled out in detail in regulations published in the Federal Register on August 23, 1977, by the U.S. Department of Health, Education and Welfare.* Despite this detail, the regulations leave a number of options to the states. Each state has exercised its options through statutes and/or regulations of its own. Therefore, the most complete description of special education law as it functions locally can be found in the state administrative code. Copies of the state regulations should be available in each local school district, which may be a less formidable place to start looking than a law library.

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* Copies are $1.50 each and may be obtained from the Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402.

The other major piece of federal legislation which established basic rights for persons with disabilities is Section 504 of the Rehabilitation Act of 1973, as amended (also discussed in Unit 1). This section bars discrimination against persons with disabilities by any public or private agency receiving federal funds. Section 504 was implemented by more than sixty pages of regulations which were published in the Federal Register on May 4, 1977.* These regulations apply without modification in all of the states and territories.

In addition to these basic federal statutes, many states have passed laws which establish additional rights for persons with disabilities within their borders. Some of these statutes prohibit discrimination against persons with disabilities in such areas as zoning, voting rights, transportation, guardianship and marriage, while others require that newly constructed buildings be free of architectural barriers. Therefore, the advocate must examine the statutes and regulations in these areas as they are written in his or her state.

Other Legal Information

While every advocate for children with disabilities needs some basic knowledge of those children's legal rights, many do not have the time or inclination to become serious students of the law, but rather, need to know how it applies in specific situations. This information can be gained in several ways.

Every state has a network of legal service or legal aid societies which were set up to provide legal representation to persons who can not afford to pay for it. Many local legal service agencies have represented low-income persons with disabilities and have a fairly extensive knowledge of disability law. A telephone call to such an agency can often yield the answer to a specific legal question or a referral to someone who has the answer.

Each state also has a Protection and Advocacy System (P&A) for persons with developmental disabilities. These P&As were mandated by Congress in the federal developmental disabilities legislation of 1975 to provide legal and other advocacy services to that population. Most are located in the state capitol, but many have local offices or toll free telephone numbers for easy access. In addition to providing answers to specific legal questions, many P&As provide training in disability law to consumers, parents, and other lay advocates of persons with disabilities. Generally, this training will be tailored to the stated needs of a specific group. A list of the P&A's in each state can be found at the end of this chapter in Appendix 6A.

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*Copies are $1.50 each and may be obtained from the Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402.

Because disability law varies in its details from state to state, a number of groups have published handbooks which outline how the law applies to persons with disabilities in their states. In some states, this handbook as been published by the P&A; in others, it has been published by a consumer or parents' group (listed in Appendix 5B). A contact with either generally will turn up a lead to a copy.

Finally, many national advocacy groups have published articles or summaries which describe how a particular piece of federal legislation affects the population for whom they advocate. The journals and newsletters of these national organizations are also a major resource for local advocates in keeping up with pending federal legislation and judicial decisions which have national implications for children with disabilities. Many of their publications are free or relatively inexpensive. A list of these organizations appears in Appendix 5A.

Recently, the focus of legislative advocacy for children with disabilities has shifted from the federal to the state level. As a result, advocates have had to become familiar with the state's system of decision-making. While this chapter can not provide specific information about each state's law-making process, there are a few pieces of information which should be helpful.

Each state legislature has one or more public information offices which supply an incredible amount of detail to anyone who asks them. That information includes copies of all legislation introduced, who introduced it, and where it is in the legislative process. These offices are listed in the telephone directory of the state's capitol city. They often can be reached by toll-free numbers.

The major source of information in this system, of course, is your local state legislator. He or she usually has a local office, staffed with persons anxious to answer questions and learn constituents' opinions. That's how they get reelected.

Attorneys and Legal Services

Most children with disabilities are denied their rights because parents or professionals are ignorant of the law. The knowledgeable advocate can redress most grievances. Occasionally, however, legal intervention is necessary. The P.L. 94-142 regulations require schools to inform parents of any free or low cost legal services, if they request this information or initiate a due process hearing. Two sources of legal representation, P&As and legal aid societies, have been mentioned already. Because each has limited resources, they both identify other sources of legal assistance in their communities to meet needs which they can not handle or to serve populations not covered by their respective mandates. Therefore, both are excellent places to start when seeking legal representation for a child with a disability.

In some states and local communities, the private bar actively encourages its members to provide free or low-cost counsel to those who can not afford it. Such services can be located through P&As, legal aid societies, and state and local bar associations. The latter can also identify attorneys who specialize in disability law for the client with sufficient funds to pay regular legal fees.

Throughout the country, there are a number of public interest law firms which provide legal information and representation to various sectors of the disability community. While their funds are limited and they tend to concentrate their resources on precedent-setting cases, they are part of a larger legal network serving persons with disabilities and, therefore, often can identify local legal resources. Several are listed in Appendix 6B.

Advocacy Networks

The advocate who is seeking social change to benefit children and youth with disabilities is in need of allies who share similar goals. Fortunately, this country and each of its states and their local communities are crisscrossed by networks of individuals and organizations interested in systems advocacy on behalf of children and youth with disabilities. The task for the new advocate is to identify those networks and link up with the ones which share his or her specific interests. Like all networks, one strand eventually leads to all others. Here are a few ways into the web.

Major disabilities which affect children have served as the focal point around which many of their parents organize to protect those children's rights, improve services to them, and stimulate research for the prevention or cure of those disabilities. Organizations such as the national Association for Retarded Citizens (ARC) and United Cerebral Palsy Association (UCPA) maintain government affairs offices in Washington, D.C., staffed by competent lobbyists. Most of these organizations have state offices, as well as local chapters throughout the country. One of the major functions of the state offices is to inform state legislators and administrators of the needs of children and youth with disabilities. Local chapters often perform the same function at their level and support the state and national offices in their efforts by involving parents in the legislative process. The strength of these organizations varies from state to state, but most states have several such groups which are active in systems advocacy.

In the last fifteen years, persons with disabilities have begun to organize themselves for political action. Thousands of their groups are scattered throughout the country. Many are affiliated with a particular disability, while others are organized across disability lines. Some have joined together to form the American Coalition of Citizens with Disabilities (ACCD) which represents their interests in Washington, D.C. These groups often work closely with the state and local parents' groups mentioned above. Often they are known to the P&A in their state as well.

With the passage of Public Law 94-142, the local school district has become the focus of many services to children with disabilities and in many districts the parents of these youngsters have formed local groups to improve services. Parent groups are usually known to the special educators in those districts.

The number of organizations promoting the rights of children with disabilities is endless. Contact with one, followed by a few well-chosen questions, will usually link the inquiring advocate with the group or resource he or she is looking for.

ADVOCACY ROLES AND MODELS

As the health professional and special educator become more deeply involved in advocacy for children and youth with disabilities, they discover they are joining many others who also advocate on behalf of children, youth, and adults with disabilities. It is important to know what these other advocates do and what they call what they do.

What follows is an attempt to map out a typology of advocacy for children and youth with disabilities, to describe the various roles of advocates, and to define some of the terminology which has grown up in the field of advocacy since the courts began to recognize the rights of persons with disabilities. This closing section might be called "Who Does What For Whom."

In trying to make the distinctions as sharp as possible, advocacy roles and models will be examined from several angles. Advocacy activities then will be classified in terms of whether they serve individuals or groups, followed by an examination of how advocacy is accomplished (individually or collectively). The unit will close with a discussion of the persons commonly involved in the various forms of advocacy and how their roles sometimes overlap. This may involve some repetition. Hopefully, the repetition will make the distinctions clearer.

Individual Advocacy or "case advocacy" is advocacy on behalf of individuals with disabilities and includes:

- Provision of generic or functional services

- Counseling and support--Citizen Advocacy and Peer Counseling
- Coordination of generic services--case management
- Lay representation--informal and formal due process proceedings
- Legal representation--for due process proceedings; litigation
- Protective Services--intervention against abuse and neglect

Collective Advocacy or "class advocacy" is advocacy on behalf of groups of persons with disabilities and may involve the following activities:

- Planning and administration of generic services
- Mutual support
- Systems advocacy--administrative coordination and rulemaking; legislation
- Standard setting and enforcement; licensure
- Class action litigation

In each category above, the types of advocacy have been arranged along a continuum beginning with those which are the least formal and ending with those which employ the most formal proceedings and enforcement measures. To some extent, the involvement of volunteer versus professional advocates parallels this continuum with the volunteers being more heavily involved in the first-listed types in each category and the professionals in those listed later. However, this distinction is frail enough to begin many arguments and to resolve very few. The following is a brief description of each of the activities listed and how they have earned their practitioners' claims for inclusion under the umbrella term, advocacy.

INDIVIDUAL ADVOCACY

Provisions of Generic Services

Few of the services received by a person with a disability are delivered in a vacuum. Generally, the service providers are linked together formally or informally and the service provided by one impacts upon the way others may deliver theirs. Each develops a unique understanding of the person with a disability and his or her needs. To the extent the individual service provider uses that understanding to improve the totality of services provided, he or she is an advocate for the client. The dietician who sees a patient having difficulty with a knife or fork and suggests an occupational therapy evaluation is an advocate at the most basic level. The lab technician who spots a barely perceptible limp which, on examination, proves to be evidence of an undetected stroke is an advocate. Both have transcended their normal professional duties to obtain better services for the persons under their care.

Counseling and Support—Citizen Advocacy and Peer Counseling

Counseling in the generic sense of providing guidance and psychological support can be adjunct to advocacy when it is used to help the person with a disability or his or her parent(s) to clarify goals and gather the strength to pursue them. In varying degrees of intensity, counselors, friends, and other professionals provide this advocacy service.

In addition, there are two programs of support which have become formalized enough to be recognized as sub fields within advocacy. The first, Citizen Advocacy, was developed to provide support to young persons and adults with mental retardation so that they can live more independently. Most Citizen Advocacy programs are sponsored by local Associations for Retarded Citizens, but an increasing number are being developed to serve others with developmental and related disabilities, either by volunteer agencies such as United Cerebral Palsy Associations or by the Developmental Disabilities Protection and Advocacy (P&A) Systems.

These programs generally employ volunteers on a one-to-one basis who provide support and companionship to a person with a disability called a protege. The volunteer may perform other services for the protege to improve the skills he or she needs to function more independently. These may include tutoring or less formal training in reading and language arts, grooming and personal hygiene, money management, shopping, and meal preparation. In some instances, the Citizen Advocate may intercede on the disabled person's behalf with community institutions and social service agencies to increase their understanding and acceptance of that person. In conflict situations, the Citizen Advocate may speak on his or her behalf as a lay advocate and some programs engage in systems advocacy to change the community response to persons with disabilities as a group.

The second, Peer Counseling, has grown out of the Independent Living movement. In this program, persons with disabilities who have succeeded in living independently share their skills and experiences in a counseling relationship with others who have recently become disabled and/or who are trying to achieve a greater degree of independence. The sophistication of this program, like that of Citizen Advocacy programs varies with the degree of training of the helping person and the complexity of the problems of the person he or she is helping. Some peer counselors are paid and others are volunteers depending on the philosophy and/or funding level of the program in which they work.

Coordination of Generic Services—Case Management

Some disabling conditions require complex interrelated services over an extended period of time. The person coordinating the delivery of these services for a particular disabled person has recently come to be called a case manager. Usually, although not always, trained in social work, this person is charged with negotiating his or her client's way through an often disjointed network of human service agencies and insuring that there disparate services are somehow tailored to meet the client's very individual needs. This is a very specific advocacy role which has developed to serve persons with developmental disabilities. To some extent these same skills are used, generally over a shorter period of time, by the vocational rehabilitation counselor in coordinating the variety of services a person with a disability needs to prepare for and obtain employment.

Lay Representation—Lay Advocacy

Many of the federal and state programs providing services to persons with disabilities have a variety of eligibility requirements. The denial of service under them may be appealed through a variety of due process proceedings. In addition, such proceedings may also be used by disabled persons or their parents who are dissatisfied with the services they are receiving from those programs. For example, both the Social Security System which provides supplemental or maintenance income to persons with disabilities and P.L. 94-142 which guarantees a free and appropriate education to youngsters with handicapping conditions have such due process proceedings outlined in their implementing regulations.

In many cases, the first steps of such proceedings are designed to be informal and encourage negotiation of differences before the position of each party hardens. Still, the service provider is generally represented in those proceedings by professionals who are better versed in the services provided and the laws and regulations that govern their provision than are the persons with disabilities who receive them or their parents.

As a result, a number of groups have trained lay advocates to represent or otherwise assist in such proceedings. These persons have a specific knowledge of the statutes and regulations in a particular area of disability law and a familiarity with the professional disciplines providing the services in question. Often they are parents or disabled persons themselves who have gone through the process on their own behalf or that of their child. In some cases, they are backed up by attorneys who provide guidance and/or step in when the proceedings become so formal as to require a lawyer. Many of the P&A Systems for persons with developmental disabilities have provided the training for and served as backup to such groups which they refer to as Advocacy Networks.

Legal Representation

When such proceedings become formal or when the regulations require it, the services of an attorney are needed to obtain the appropriate services for a person with a disability or to protect his or her human and civil rights. The Protection and Advocacy Systems have been established by Congress to provide that service to persons with developmental disabilities. A number of states have expanded the P&A mandate to include persons with other disabilities. All have the capacity to bring legal action, either directly or through contact with private attorneys or legal service agencies. In some states, legal service agencies have projects which specifically serve persons with disabilities. In some others, state or local bar associations take the responsibility.

Protective Services

Advocacy and law enforcement combine in programs which protect classes of persons who particularly are vulnerable to abuse and neglect. Begun to protect children, many such programs have expanded to cover the elderly, nursing home residents, and pesons with mental retardation. Generally, they are a function of state government. Included as protective services are also those agencies which provide guardianship services for those persons who, by reason of mental incompetence or severe physical incapacity, are unable to make decisions for themselves. Like other protective services, some guardianship programs are designed specifically to serve persons with disabilities. Other programs are set up to serve persons with disabilities if they belong to another protected class, such as children in foster care.

COLLECTIVE ADVOCACY

Planning of Generic Services

At the governmental level, there are many services designed for able-bodied persons which play an important part in a comprehensive service network for persons with disabilities. Health care systems and income maintenance programs are but two examples. Increasingly, planners and administrators of programs which serve persons with disabilities have interceded with these larger programs to redesign their services so that they will be more accessible and more responsive to the particular needs which arise from those disabilities. This advocacy function is largely carried out in the public and private sectors of the human services community and it employs the tools of planning and administration in gentle persuasion. If it were not so sequestered and so gentle, it would be classified as systems advocacy (see below). Many do call it that.

Mutual Support

Historically, the eariest advocates for persons with disabilities were the national, state and local voluntary agencies and associations formed by parents to assist their children with specific disabilities. While these groups now provide a wide range of services and engage in a number of advocacy functions such as lobbying and bringing class action litigation, many still fulfill the purpose for which they were originally formed: to provide mutual support for persons with disabilities and/or their parents. As responsibility for services to persons with disabilities has shifted from the private to the public sector, many of the earlier groups shifted their focus and many new groups have formed. For example, when services were primarily private, parents banded together to form Associations for Retarded Citizens and United Cerebral Palsy Associations. Now parent groups tend to form across disability lines to address the problems of special education in a particular school district or to lobby for changes in state laws. As an adjunct to these purposes, parent groups also serve as a source of information and support for new parents of children with disabilities along with some of the more traditional associations. Consumer groups of persons with disabilities perform these information and mutual support functions for their members as well.

Systems Advocacy

Systems advocacy, literally making changes in the system on behalf of persons with disabilities, takes many forms. Systems advocacy ranges from educating the public to changing attitudes toward persons with disabilities to lobbying for legislation to protect old rights or establish new ones. All forms of systems advocacy require the same skills. The greatest number of disparate advocacy functions are subsumed under this definition.

Class Action Litigation

Class action litigation includes legal actions brought in the name of specific individuals on behalf of a larger class of persons adversely affected by similar circumstances and who will benefit by the same or similar relief. Class actions often have the powerful potential for redefining the rights of even larger groups of persons and, therefore, are seen as popular advocacy tools. Recent experience has shown them to be costly and time-consuming to pursue and the judgments resulting from them difficult to enforce. Historically, they have played a major role in establishing the rights of persons with disabilities.

Standard Setting and Licensure

The collective form of advocacy in protective services involves the setting of standards for the facilities which provide services to persons with disabilities and the licensing of the professionals who provide those services. The standard-setting process is a legislative or administrative function of state or federal governments and is often the target of systems advocates who seek to improve services to persons with disabilities. The enforcement of such standards is generally a function of state government which often requires monitoring by advocates to be effective.

ROLES IN ADVOCACY

Identifying the "who" in who does what in advocacy is, perhaps, the most slippery part of the exercise since roles overlap considerably. Generally, there are three types of people who engage in advocacy: (1) attorneys and associated professional advocates; (2) health and human service professionals; and (3) persons with disabilities, their parents, relatives, and friends.

Lawyers obviously litigate and individual suits and class action litigation is exclusively their advocacy territory. Less obviously, they assist systems advocates by analyzing proposed legislation, administrative regulations, and formal agreements between government agencies for the provision or coordination of services. They also may act as the trainers of lay advocates.

A relatively new professional advocate in the field is the community organizer who assists consumers in designing and carrying out more effective strategies for change. This professional works almost exclusively in systems advocacy, though his or her efforts also may improve a group's capacity for information-sharing and mutual support.

Health and human service professionals plan, coordinate, and deliver services to persons with disabilities. They provide supportive counseling and may be involved in standard setting and enforcement as well as various aspects of protective services depending on their profession. In addition, through their professional societies, they are active in lobbying for the general improvement of conditions for persons with disabilities. Thus, they are systems advocates as well. As the relative or friend of persons with disabilities, they may assume additional advocacy roles.

Consumers with disabilities, their relatives, friends, and interested volunteers act as counselors, and provide mutual support. They are lay advocates in due process proceedings. They take the lead in systems advocacy and fill the largest number of roles in that area.

CONCLUSION

This article has attempted to emphasize the diverse roles health and education professionals may assume in the advocacy process. The concept of advocacy, advocacy models and resources, barriers to and solutions for effective advocacy have been presented. Due to the nature of the health and education professions, advocacy is an integral, life-long role for health care providers and educators. It is hoped that this unit enables practitioners to use their skills and contacts more effectively on behalf of those with disabilities.

REFERENCES

Boggs, Elizabeth Monroe. "Protection and Advocacy in the Context of Its Legislative History" in Advocacy Systems for Persons with Disabilities: Context, Components, and Resources. 1976, Texas Tech University, Lubbock, TX.

Common Sense and Everyday Ethics. 1980, American Viewpoint, Inc., Washington, D.C., p. 5.

ADDITIONAL READINGS

How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies. The Coordinating Council for Handicapped Children. Price $4.00 plus $.60 postage.

Tells how to be an effective advocate and organizer, how to lobby and more.

Mental and Developmental Disabilities Directory of Legal Advocates. 1982 version. American Bar Association Committee on the Mentally Retarded. 18 pp. Price $3.00.

State by state listing of attorneys, legal clinics and

"Politics - The Name of the Game" by Frederick J. Weintraub

"The Professional Educator and the Political Process" by Philip R.Jones

"Litigation" by Alan Abeson

These three articles are chapters in Public Policy and the Education of Exceptional Children. 1975, Edited by Frederick J. Weintraub, Alan Abeson, Joseph Ballard, and Martin L. LaVor. Council for Exceptional Children. 378 pp. Price $16.35, members $13.90.

Reflections on Growing Up Disabled. Reginald Jones, Editor. Council for Exceptional Children. 112 pp. Price $7.50, members $6.38.

A unique sharing of the childhood feelings, insights, and self perceptions by people with disabilities. Frustrations related to learning and socialization are expressed. Parent views of the way things have changed over the last decade and the misconceptions that continue to prevail are also included.

APPENDICES

ADDRESSES FOR PUBLICATIONS

Allyn and Bacon
470 Atlantic Avenue
Boston, MA 02210

American Bar Association
Committee on the Mentally Retarded
1800 M Street, N. W.
Washington, D. C. 20036

Board of Cooperative Educational Services
Putnam/Northern Westchester
Yorktown Heights, NY 10598

Charles B. Slack, Inc.
6900 Grove Road
Thorofare, NJ 08086

Cummings Publishing Company
2727 Sand Hill Road
Menlo Park, CA 94025

Education Commission of the States
1860 Lincoln Street
Suite 300
Denver, CO 80295

Houghton Mifflin Company
One Deacon Street
Boston, MA 02107

National Association of State Directors of
Special Education, Inc.
101-16th Street, N. W.
Washington, D. C. 20036

National Textbook Company
8259 Niles Center Road
Skokie, IL 60077

Project Head Start
U. S. Government Printing Office
Washington, D. C. 20402

Scott, Foresman, and Company
1900 E. Lake Avenue
Glenview, IL 60025

The Coordinating Council for Handicapped Children
407 S. Dearborn, Room 680
Chicago, IL 60605

The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

United Cerebral Palsy Associations, Inc.
66 East 34th Street
New York, NY 10016

U. S. Department of Education
Office for Civil Rights
Switzer Bldg.
330 C Street, S. W.
PRAS/ITAD
Washington, D. C. 20202

W. B. Saunders Company
W. Washington Sq.
Philadelphia, PA 19105

SELECTED P.L. 94-142 REGULATIONS AND THEIR IMPLICATIONS FOR HEALTH PROFESSIONALS

REGULATION	IMPLICATION
300.2 Applicability to State, local, and private agencies. (b) *Public agencies within the State.* The annual program plan is submitted by the State educational agency on behalf of the State as a whole. Therefore, the provisions of this part apply to all political subdivisions of the State that are involved in the education of handicapped children. These would include: (1) The State educational agency, (2) local educational agencies and intermediate educational units, (3) other State agencies and schools (such as Departments of Mental Health and Welfare and State schools for the deaf or blind), and (4) State correctional facilities. *Comment.* The requirements of this part are binding on each public agency that has direct or delegated authority to provide special education and related services in a State that receives funds under Part B of the Act, regardless of whether that agency is receiving funds under Part B.	It is sometimes thought that P.L. 94-142 only applies to education agencies. This section of the regulation clarifies the role of other agencies by which health-related professionals may be employed. The State education agency, however, is responsible for insuring that the requirements of this law are carried out.
300.12 Qualified. As used in this part, the term "qualified" means that a person has met State educational agency approved or recognized certification, licensing, registration, or other comparable requirements which apply to the area in which he or she is providing special education or related services.	Allied or health-related professionals who provide "related services" to youngsters with handicaps must be authorized to do so by the State education agency.
300.13 Related services. (a) As used in this part, the term "related services" means transportation and such developmental, corrective, and other supportive services as are required to assist a handicapped child to benefit from special education, and includes speech pathology and audiology, psychological services, physical and occupational therapy, recreation, early identification and assessment of disabilities in children, counseling services, and medical services for diagnostic or evaluation purposes. The term also includes school health services, social work services in schools, and parent counseling and training. (b) The terms used in this definition are defined as follows: (1) "Audiology" includes: (i) Identification of children with hearing loss; (ii) Determination of the range, nature, and degree of hearing loss, including referral for medical or other professional attention for the habilitation of hearing;	"Related Services" is the term used in this law to describe the kinds of services usually provided by health professionals. They are called "related services" if they are "required to assist a handicapped child to benefit from special education." The law does not require that services such as those listed be provided otherwise. For example, physical therapy may be provided for a child in a wheelchair who is enrolled in a regular 5th grade and does not need special education. In this case, the physical therapy would not be considered a "related service" and the child, although disabled, would not be considered "handicapped" for purposes of this law. As discussed earlier, the purpose of the law, is to insure that all children with

(iii) Provision of habilitative activities, such as language habilitation, auditory training, speech reading (lip-reading), hearing evaluation, and speech conservation;

(iv) Creation and administration of programs for prevention of hearing loss;

(v) Counseling and guidance of pupils, parents, and teachers regarding hearing loss; and

(vi) Determination of the child's need for group and individual amplification, selecting and fitting an appropriate aid, and evaluating the effectiveness of amplification.

(2) "Counseling services" means services provided by qualified social workers, psychologists, guidance counselors, or other qualified personnel.

(3) "Early identification" means the implementation of a formal plan for identifying a disability as early as possible in a child's life.

(4) "Medical services" means services provided by a licensed physician to determine a child's medically related handicapping condition which results in the child's need for special education and related services.

(5) "Occupational therapy" includes:

(i) Improving, developing or restoring functions impaired or lost through illness, injury, or deprivation;

(ii) Improving ability to perform tasks for independent functioning when functions are impaired or lost; and

(iii) Preventing, through early intervention, initial or further impairment or loss of function.

(6) "Parent counseling and training" means assisting parents in understanding the special needs of their child and providing parents with information about child development.

(7) "Physical therapy" means services provided by a qualified physical therapist.

(8) "Psychological services" include:

(i) Administering psychological and educational tests, and other assessment procedures;

(ii) Interpreting assessment results;

(iii) Obtaining, integrating, and interpreting information about child behavior and conditions relating to learning.

(iv) Consulting with other staff members in planning school programs to meet the special needs of children as indicated by psychological tests, interviews, and behavioral evaluations; and

(v) Planning and managing a program of psychological services, including psychological counseling for children and parents.

(9) "Recreation" includes:

(i) Assessment of leisure function;

(ii) Therapeutic recreation services;

(iii) Recreation programs in schools and community agencies; and

(iv) Leisure education.

(10) "School health services" means services provided by a qualified school nurse or other qualified person.

(11) "Social work services in schools" include:

(i) Preparing a social or developmental history on a handicapped child;

(ii) Group and individual counseling with the child and family;

(iii) Working with those problems in

handicaps have available to them a free appropriate public education which includes special education and related services to meet their unique needs. The child in this example, is receiving an appropriate education and therapy needs are not related to his/her educational program.

Health professionals should be familiar with this list of related services, although it is not exhaustive, so they can help inform parents about them, be aware of some of the other professionals with whom to coordinate, and be able to make referrals to other professionals or agencies when appropriate.

a child's living situation (home, school, and community) that affect the child's adjustment in school; and

(iv) Mobilizing school and community resources to enable the child to receive maximum benefit from his or her educational program.

(12) "Speech pathology" includes:

(i) Identification of children with speech or language disorders;

(ii) Diagnosis and appraisal of specific speech or language disorders;

(iii) Referral for medical or other professional attention necessary for the habilitation of speech or language disorders;

(iv) Provisions of speech and language services for the habilitation or prevention of communicative disorders; and

(v) Counseling and guidance of parents, children, and teachers regarding speech and language disorders.

(13) "Transportation" includes:

(i) Travel to and from school and between schools,

(ii) Travel in and around school buildings, and

(iii) Specialized equipment (such as special or adapted buses, lifts, and ramps), if required to provide special transportation for a handicapped child.

Comment. With respect to related services, the Senate Report states:

> The Committee bill provides a definition of "related services," making clear that all such related services may not be required for each individual child and that such term includes early identification and assessment of handicapping conditions and the provision of services to minimize the effects of such conditions.

(Senate Report No. 94–168, p.12 (1975).)

The list of related services is not exhaustive and may include other developmental, corrective, or supportive services (such as artistic and cultural programs, and art, music, and dance therapy), if they are required to assist a handicapped child to benefit from special education.

There are certain kinds of services which might be provided by persons from varying professional backgrounds and with a variety of operational titles, depending upon requirements in individual States. For example, counseling services might be provided by social workers, psychologists, or guidance counselors; and psychological testing might be done by qualified psychological examiners, psychometrists, or psychologists, depending upon State standards.

Each related service defined under this part may include appropriate administrative and supervisory activities that are necessary for program planning, management, and evaluation.

300.14 Special education.

(a) (1) As used in this part, the term "special education" means specially designed instruction, at no cost to the parent, to meet the unique needs of a handicapped child, including classroom instruction, instruction in physical education, home instruction, and instruction in hospitals and institutions.

(2) The term includes speech pathology, or any other related service, if the service consists of specially designed instruction, at no cost to the parents, to meet the unique needs of a handicapped child, and is considered "special education" rather than a "related service" under State standards.

(3) The term also includes vocational education if it consists of specially designed instruction, at no cost to the parents, to meet the unique needs of a handicapped child. • • •

Paragraph 2 of this section explains that some related services may be considered "special education". State policies should be consulted for clarification as States usually determine when a service is considered special education rather than a related service.

300.126 Full educational opportunity goal—facilities, personnel, and services.

(a) *General requirement*. Each annual program plan must include a description of the kind and number of facilities, personnel, and services necessary throughout the State to meet the goal of providing full educational opportunity for all handicapped children.

(2) The number of other additional personnel needed, and the number currently employed in the State, including school psychologists, school social workers, occupational therapists, physical therapists, home-hospital teachers, speech-language pathologists, audiologists, teacher aides, vocational education teachers, work study coordinators, physical education teachers, therapeutic recreation specialists, diagnostic personnel, supervisors, and other instructional and non-instructional staff. • • •

(4) The number and kind of facilities needed for handicapped children and the number and kind currently in use in the State, including regular classes serving handicapped children, self-contained classes on a regular school campus, resource rooms, private special education day schools, public special education day schools, private special education residential schools, public special education residential schools, hospital programs, occupational therapy facilities, physical therapy facilities, public sheltered workshops, private sheltered workshops, and other types of facilities.

This section pertains to the "State plan". Each state must submit a detailed plan to the federal government to receive its share of P.L. 94-142 funds. The plan is now required every three (3) years; data updates are submitted annually. Personnel and facility needs must be thoroughly documented. The excerpts included here pertain to health and other related services personnel and facilities.

300.134 Responsibility of State educational agency for all educational programs.

(a) Each annual program plan must include information which shows that the requirements in 300.600 of Subpart F are met.

(b) The information under paragraph (a) of this section must include a copy of each State statute, State regulation, signed agreement between respective agency officials, and any other document that shows compliance with that paragraph.

The State plan must also contain copies of "interagency agreements": agreements between the State education agency and other agencies that provide special education or related services, spelling out the responsibilities of each party. The State plan, including interagency agreements, are public documents. Related health professionals interested in the details of their agency's agreement should contact the State education agency for the location of the nearest State plan.

300.137 Procedures for consultation.

Each annual program plan must include an assurance that in carrying out the requirements of section 612 of the Act, procedures are established for consultation with individuals involved in or concerned with the education of handicapped children, including handicapped individuals and parents of handicapped children.

The regulations require the States to consult with others in implementing the law. Health professionals should be involved in this procedure.

LOCAL EDUCATIONAL AGENCY APPLICATIONS—CONTENTS

300.220 Child identification.

Each application must include procedures which insure that all children residing within the jurisdiction of the local educational agency who are handicapped, regardless of the severity of their handicap, and who are in need of special education and related services are identified, located, and evaluated, including a practical method of determining which children are currently receiving needed special education and related services and which children are not currently receiving needed special education and related services.

Comment. The local educational agency is responsible for insuring that all handicapped children within its jurisdiction are identified, located, and evaluated, including children in all public and private agencies and institutions within that jurisdiction. Collection and use of data are subject to the confidentiality requirements in §§300.560–300.576 of Subpart E.

Each local education agency must prepare and submit to the State education agency a local application for P.L. 94-142 funds. This application, like the State plan, is a public document. Copies are located in the administrative offices of every school district.

Health care professionals will be especially interested in the child identification section as this area is one of the major referral points between education and health agencies.

300.223 Facilities, personnel, and services.

Each application must provide a description of the kind and number of facilities, personnel, and services necessary to meet the goal in 300.222.

As in the State plan, each local application must document the personnel, facilities, and services needed to serve its children with handicaps, including related services.

300.224 Personnel development.

Each application must include procedures for the implementation and use of the comprehensive system of personnel development established by the State educational agency.

The comprehensive system of personnel development is described below. It is important for health care professionals to know that the CSPD is a part of every local application.

PUBLIC PARTICIPATION

300.280 Public hearings before adopting an annual program plan.

(a) Prior to its adoption of an annual program plan, the State educational agency shall:

(1) Make the plan available to the general public,

(2) Hold public hearings, and

(3) Provide an opportunity for comment by the general public on the plan.

300.281 Notice.

(a) The State educational agency shall provide notice to the general public of the public hearings.

(b) The notice must be in sufficient detail to inform the public about:

(1) The purpose and scope of the annual program plan and its relation to Part B of the Education of the Handicapped Act,

(2) The availability of the annual program plan,

(3) The date, time, and location of each public hearing,

(4) The procedures for submitting written comments about the plan, and

(5) The timetable for developing the final plan and submitting it to the Commissioner for approval.

(c) The notice must be published or announced:

(1) In newspapers or other media, or both, with circulation adequate to notify the general public about the hearings, and (2) Enough in advance of the date of the hearings to afford interested parties throughout the State a reasonable opportunity to participate.

300.282 Opportunity to participate; comment period.

(a) The State educational agency shall conduct the public hearings at times and places that afford interested parties throughout the State a reasonable opportunity to participate.

(b) The plan must be available for comment for a period of at least 30 days following the date of the notice under 300.281.

The next five (5) sections of the regulations describe the State education agency procedures to insure public participation in developing its plan to educate all children with handicaps in the State. Health care providers interested in reviewing and commenting on the plan should contact the State education agency for specific times and dates of public hearings.

300.283 Review of public comments before adopting plan.

Before adopting its annual program plan, the State educational agency shall:

(a) Review and consider all public comments, and

(b) Make any necessary modifications in the plan.

300.284 Publication and availability of approved plan.

After the Commissioner approves an annual program plan, the State educational agency shall give notice in newspapers or other media, or both, that the plan is approved. The notice must name places throughout the State where the plan is available for access by any interested person.

300.344 Participants in meetings.

(a) *General.* The public agency shall insure that each meeting includes the following participants:

(1) A representative of the public agency, other than the child's teacher, who is qualified to provide, or supervise the provision of, special education.

(2) The child's teacher.

(3) One or both of the child's parents, subject to 300.345.

(4) The child, where appropriate.

(5) Other individuals at the discretion of the parent or agency.

(b) *Evaluation personnel.* For a handicapped child who has been evaluated for the first time, the public agency shall insure:

(1) That a member of the evaluation team participates in the meeting; or

(2) That the representative of the public agency, the child's teacher, or some other person is present at the meeting, who is knowledgeable about the evaluation procedures used with the child and is familiar with the results of the evaluation.

This section refers to the meeting at which the child's individualized education program (IEP) is developed. Of particular importance to health care professionals is section (b). The involvement of health related professionals as evaluators in IEP meetings has implications for institutions of higher education to develop programs where the communication, decision-making, advocacy, and other skills needed in this process are developed.

COMPREHENSIVE SYSTEM OF PERSONNEL DEVELOPMENT

300.380 Scope of system.

Each annual program plan must include a description of programs and procedures for the development and implementation of a comprehensive system of personnel development which includes:

(a) The inservice training of general and special educational instructional, related services, and support personnel;

(b) Procedures to insure that all personnel necessary to carry out the purposes of the Act are qualified (as defined in 300.12 of Subpart A) and that activities sufficient to carry out this personnel development plan are scheduled . . .

300.381 Participation of other agencies and institutions.

(a) The State educational agency must insure that all public and private institutions of higher education, and other agencies and organizations (including representatives of handicapped, parent, and other advocacy organizations) in the State which have an interest in the preparation of personnel for the education of handicapped children, have an opportunity to participate fully in the development, review, and annual updating of the comprehensive system of personnel development.

(b) The annual program plan must describe the nature and extent of participation under paragraph (a) of this section and must describe responsibilities of the State educational agency, local educational agencies, public and private institutions of higher education, and other agencies . . .

300.382 Inservice training.

(a) As used in this section, "inservice training" means any training other than that received by an individual in a full-time program which leads to a degree . . .

(f) Each annual program plan must:

(1) Describe the process used in determining the inservice training needs of personnel engaged in the education of handicapped children;

(2) Identify the areas in which training is needed (such as individualized education programs, non-discriminatory testing, least restrictive environment, procedural safeguards, and surrogate parents);

(3) Specify the groups requiring training (such as special teachers, regular teachers, administrators, psychologists, speech-language pathologists, audiologists, physical education teachers, therapeutic recreation specialists, physical therapists, occupational therapists, medical personnel, parents, volunteers, hearing officers, and surrogate parents);

These four (4) sections describe the personnel development requirements of P.L. 94-142. These provisions were written to insure that qualified personnel would be available in sufficient numbers to meet the education and related health needs of children with handicaps. Four points are crucial for health care professionals:

1. Related service providers must be included in the needs assessment required by this section, whether or not they are employed by education agencies.

2. If training needs of related service providers are identified, then inservice training must be designed to meet those needs.

3. Other agencies must have an opportunity to participate in planning and comprehensive system of personnel development.

4. The State education agency may contract with other agencies to deliver inservice training.

300.383 Personnel development plan.

Each annual program plan must: (a) Include a personnel development plan which provides a structure for personnel planning and focuses on preservice and inservice education needs;

(b) Describe the results of the needs assessment under 300.382(b)(1) with respect to identifying needed areas of training, and assigning priorities to those areas; and

(c) Identify the target populations for personnel development, including general education and special education instructional and administrative personnel, support personnel, and other personnel (such as paraprofessionals, parents, surrogate parents, and volunteers)

300.500 Definition of "evaluation."

As used in this part...

"Evaluation" means procedures used in accordance with 300.530–300.534 to determine whether a child is handicapped and the nature and extent of the special education and related services that the child needs. The term means procedures used selectively with an individual child and does not include basic tests administered to or procedures used with all children in a school, grade, or class.

Assessment of disabilities is a major service provided by health care providers. According to this definition such assessment is intended to determine whether the youngster is handicapped for purposes of this law; i.e., in need of special education and related services. State education agency eligibility criteria must be used in making such assessments.

PROTECTION IN EVALUATION PROCEDURES

300.530 General.

(a) Each State educational agency shall insure that each public agency establishes and implements procedures which meet the requirements of 300.530–300.534.

(b) Testing and evaluation materials and procedures used for the purposes of evaluation and placement of handicapped children must be selected and administered so as not to be racially or culturally discriminatory.

300.531 Preplacement evaluation.

Before any action is taken with respect to the initial placement of a handicapped child in a special education program, a full and individual evaluation of the child's educational needs must be conducted in accordance with the requirements of 300.532.

300.532 Evaluation procedures.

State and local educational agencies shall insure, at a minimum, that:

(a) Tests and other evaluation materials:

(1) Are provided and administered in the child's native language or other mode of communication, unless it is clearly not feasible to do so;

While these provisions describe the rights of the person with a disability during the evaluation process, they also describe the procedures health care professionals who conduct evaluations must follow. Hence, they are included in this analysis. Section 300.530 prohibits discrimination in assessment. Section 300.531 requires that an assessment be conducted prior to placement or the delivery of services. Section 300.532 sets forth very specific procedures regarding the selection and administration of tests and assessment instruments, and the personnel involved in the assessment process.

(2) Have been validated for the specific purpose for which they are used; and

(3) Are administered by trained personnel in conformance with the instructions provided by their producer;

(b) Tests and other evaluation materials include those tailored to assess specific areas of educational need and not merely those which are designed to provide a single general intelligence quotient;

(c) Tests are selected and administered so as best to ensure that when a test is administered to a child with impaired sensory, manual, or speaking skills, the test results accurately reflect the child's aptitude or achievement level or whatever other factors the test purports to measure, rather than reflecting the child's impaired sensory, manual, or speaking skills (except where those skills are the factors which the test purports to measure);

(d) No single procedure is used as the sole criterion for determining an appropriate educational program for a child; and

(e) The evaluation is made by a multidisciplinary team or group of persons, including at least one teacher or other specialist with knowledge in the area of suspected disability.

(f) The child is assessed in all areas related to the suspected disability, including, where appropriate, health, vision, hearing, social and emotional status, general intelligence, academic performance, communicative status, and motor abilities.

Comment. Children who have a speech impairment as their primary handicap may not need a complete battery of assessments (e.g., psychological, physical, or adaptive behavior). However, a qualified speech-language pathologist would (1) evaluate each speech impaired child using procedures that are appropriate for the diagnosis and appraisal of speech and language disorders, and (2) where necessary, make referrals for additional assessments needed to make an appropriate placement decision.

300.533 Placement procedures.

(a) In interpreting evaluation data and in making placement decisions, each public agency shall:

(1) Draw upon information from a variety of sources, including aptitude and achievement tests, teacher recommendations, physical condition, social or cultural background, and adaptive behavior;

(2) Insure that information obtained from all of these sources is documented and carefully considered;

(3) Insure that the placement decision is made by a group of persons, including persons knowledgeable about the child, the meaning of the evaluation data, and the placement options; and

(4) Insure that the placement decision is made in conformity with the least restrictive environment rules in 300.550-300.554.

Section 300.533 describes the use of test results for making decisions about the student's educational program and services to be provided. These are important rules for all health and other related services personnel to know whether they conduct assessments or work with parents of youngsters with disabilities in other capacities.

(b) If a determination is made that a child is handicapped and needs special education and related services, an individualized education program must be developed for the child in accordance with 300.340-300.349of Subpart C.

Comment. Paragraph (a)(1) includes a list of examples of sources that may be used by a public agency in making placement decisions. The agency would not have to use all the sources in every instance. The point of the requirement is to insure that more than one source is used in interpreting evaluation data and in making placement decisions. For example, while all of the named sources would have to be used for a child whose suspected disability is mental retardation, they would not be necessary for certain other handicapped children, such as a child who has a severe articulation disorder as his primary handicap. For such a child, the speech-language pathologist, in complying with the multisource requirement, might use (1) a standardized test of articulation, and (2) observation of the child's articulation behavior in conversational speech.

300.534 Reevaluation.

Each State and local educational agency shall insure:

(a) That each handicapped child's individualized education program is reviewed in accordance with §§ 121a.340—121a.349 of Subpart C, and

(b) That an evaluation of the child, based on procedures which meet the requirements under § 121a.532, is conducted every three years or more frequently if conditions warrant or if the child's parent or teacher requests an evaluation.

300.503 Independent educational evaluation.

(a) *General.* (1) The parents of a handicapped child have the right under this part to obtain an independent educational evaluation of the child, subject to paragraphs (b) through (e) of this section.

(2) Each public agency shall provide to parents, on request, information about where an independent educational evaluation may be obtained.

(3) For the purposes of this part:

(i) "Independent educational evaluation" means an evaluation conducted by a qualified examiner who is not employed by the public agency responsible for the education of the child in question.

(ii) "Public expense" means that the public agency either pays for the full cost of the evaluation or insures that the evaluation is otherwise provided at no cost to the parent, consistent with 300.301 of Subpart C.

(b) *Parent right to evaluation at public expense.* A parent has the right to an independent educational evaluation at public expense if the parent disagrees with an evaluation obtained by the public agency. However, the public agency may initiate a hearing under 300.506 of this subpart to show that its evaluation is appropriate. If the final decision is that the evaluation is appropriate, the parent still has the right to an independent educational evaluation, but not at public expense.

When monitoring a client's progress, managing caseloads, or scheduling appointments, health care providers should be aware of this requirement to reassess the person with disabilities at least every three (3) years.

Health professionals who provide evaluations either as employees of agencies or as private practitioners might want to contact the local education agency to be sure the agency is aware of their services for the purpose of providing information to parents about independent evaluations as required in paragraph (2) of this section.

Sometimes the school is required to pay for independent evaluations; at other times they are obtained at the parents' expense. The circumstances under which independent evaluations may be obtained at public expense is discussed in this section.

(c) *Parent initiated evaluations.* If the parent obtains an independent educational evaluation at private expense, the results of the evaluation:

(1) Must be considered by the public agency in any decision made with respect to the provision of a free appropriate public education to the child, and

(2) May be presented as evidence at a hearing under this subpart regarding that child.

(d) *Requests for evaluations by hearing officers.* If a hearing officer requests an independent educational evaluation as part of a hearing, the cost of the evaluation must be at public expense.

(e) *Agency criteria.* Whenever an independent evaluation is at public expense, the criteria under which the evaluation is obtained, including the location of the evaluation and the qualifications of the examiner, must be the same as the criteria which the public agency uses when it initiates an evaluation.

Appendix 1B

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Appendix 3A

THE REFLECTIVE RESPONSE TECHNIQUE

Definition:

A response by the listener in which he/she verbalizes back to the speaker the essential ideas and feelings the speaker has experessed. The listener acts as a mirror, reflecting back and supporting the speaker's message.

Objectives:

1. Listen not only for the words of the speaker, but for the feelings behind the words as well.

2. Try to see and understand the world through the speaker's perceptions.

3. Do not evaluate. Suspend your own value judgments, so as to understand the speaker's thoughts and feelings as he/she experiences them.

4. "Check out" your understanding by verbally and nonverbally reflecting back to the speaker the essential ideas and feelings the speaker has expressed.

5. Encourage further verbalization; support the speaker's ideas and feelings by providing additional information which you feel helps clarify the speaker's ideas and feelings.

6. The following phrases may help you get started with the reflective response technique:

   What you seem to be saying is . . .
   I think you're saying . . .

7. When sharing your own personal perceptions, use the "I Rule." Talk in terms of yourself, personalizing your conversation with yourself. The following phrases may help:

   I feel . . .
   It is my opinion . . .
   I believe . .
   To me it is . . .
   For myself . . .
   I think . . .

Appendix 3B

SELF-CONCEPT ENHANCEMENT AND COMMUNICATION

Health Provider Guidelines

1. **Facilitate client-centered case management.** Actively assist children and youth to see themselves as planning, purposing, choosing individuals, responsible and accountable. Children can grow, flourish, and develop much more readily when the significant person "projects and inherent trust and belief in their capacity to become what they have potential to become" (Hamachek, 1971, p. 202).

2. **Help children and youth identify their own particular needs, interests, and concerns; help maximize success.** Not all children will be motivated in the same way or interested in the same things; health providers need to make success more available in more different ways.

3. **Personalize your interactions.** Be sincere, uncalculating, and attuned to youngsters with disabilities as individuals.

4. **Provide the youngster with flexible, yet definite goals for success.** When limits are clear, the individual learns to rely on his/her own judgments and interpretations of events and consequences. This is particularly important for the highly anxious child who requires a structured situation in which to operate.

5. **Highlight the child's specific strengths, assets, and skills** to aid the individual in sorting out his/her own strengths and weaknesses. The child needs to know his/her own capabilities in order to gauge the probability of success.

6. **Alleviate ambiguity, disrespect, and rejection in your interactions with children and youth.**

7. **Maintain an atmosphere of warmth and acceptance.** The more positive the children's perceptions of your feelings toward them, the more positive their self-image, the better their achievement, and the more desirable their behavior.

8. **Praise yourself.** Recognize and acknowledge your own strong points in the presence of your clients. Your recognition of your own strong points will provide an impetus for your clients to praise themselves.

9. **Do not prejudge your clients. Be honest and accurate in your evaluations, while avoiding comparisons.** Your expectations for a performance is a significant determinant of how the child actually responds.

10. **Personalize evaluative comments, giving encouragement to clients.** Evaluation, whether verbal or nonverbal, which is personal, and in which the evaluator appears to take into consideration every action, attends to subtleties in behavior, and modifies his/her appraisal accordingly, should have a greater impact on the child's self-concept.

11. **Provide children with a continuous, long term exposure to a particular appraisal.** From a credible and personal source, it should have profound effects on self-concept.

12. **Provide experiences for each client to receive acceptance from peers whenever possible.**

13. **Provide experiences for clients to praise others.** Persons with high self-esteem show greater acceptance of others.

14. **Help children to evaluate themselves realistically.** Evaluation should be based on the child's comparison of his/her actual performance with his/her own personal standards, not on comparisons with others.

15. **Urge clients to concentrate on improvement, rather than perfection.**

16. **Provide experiences for children and youth to praise themselves.** Self-accepting individuals tend to have higher self-concepts. Positive self-evaluation in the form of verbal affirmations is positively related to self-concept.

Appendix 3C

TIPS FOR THE HEALTH PROFESSIONAL INTERACTING WITH YOUNGSTERS WITH DISABILITIES

The following pages contain some tips which health professionals may find useful when they interact with a child/youth with special needs. Suggestions on this page are general and apply to most children/youth with handicapping conditions. Included in the following pages are ideas intended for children/youth with specific, mild handicaps (learning disabilities and mild retardation), communication disorders, hearing impairments, visual impairments, and orthopedic impairments.

A. **General Tips:**

- Relate to the child, not just the child's label.
- Actively try to understand how the child feels.
- Accept the child and see him/her as a learner.
- Help the child feel accepted. Once the child feels accepted, he/she will usually meet your expectations if they are within his/her ability.
- Realize that your acceptance is a prerequisite to the child's acceptance of self.
- Promote friendships between the exceptional child and other children in the health-care facility.
- Expect the child to meet established rules.
- Realize that poor behavior may be caused by boredom or an inability to respond because of the mode of presentation. Maintain challenges and responsibilities.
- Be consistent; make needed modifications gradually.
- Include the child in conversations; do not shelter the child with a handicap.
- As with any child, provide successful experiences for the youngster with a disabling condition.

B. Medical Considerations:

- Maintain open communication between the parents and medical personnel. This can be very helpful in understanding the medical needs of a child.
- Know any medications taken by the child, and any possible side effects that could affect behavior or performance. For example, certain medications may cause tiredness or frequent urination.
- Be aware of the physical stamina limitations imposed on a child by a particular disabling condition. Such a child's schedule might alternate between active, stressful activities and more passive, relaxing tasks.
- Be aware that more physical energy is needed for the child with a disability to be mobile, whether that child is using crutches, braces, or a wheelchair.
- Some children may be on a specific schedule for using restroom facilities. Encourage them to meet their own needs independently (as opposed to being reminded of time schedules, etc.).
- If a child is known to have any form of epilepsy, be aware of how to deal with possible seizures. The child's parents, physician, nurse, or local epilepsy foundation can be helpful sources of information. Overall, the most important thing you can do during a seizure is to remain calm, and to explain to others present about the occurence in a matter-of-fact way.
- Regular exercise and participation in active programs is good for all children, including epilepsy, orthopedic impairments.

TIPS FOR THE HEALTH PROFESSIONAL INTERACTING WITH CHILDREN/YOUTH WITH MILD MENTAL RETARDATION

A. Presenting Information:

- Focus on the child's strengths.
- Present information in small sequential steps.
- Use several short learning periods; this is more effective than having one long period.
- Present the same concepts using a variety of materials and approaches.
- Help the child recognize how he/she can use the learned skills in daily life.
- Use a multi-modality approach whenever possible, including the use of tactile and manipulative materials.
- Include realistic practice; students learn better by doing rather than by reading or hearing about something.
- Present tasks in a clear, concise manner to increase the child's success potential.

B. Other Considerations:

- Use concrete objects whenever possible to illustrate abstractions.
- Practice on realistic materials so skills are more easily transferred. For example, real money is a more effective teaching tool than play money.
- Look for high-interest low-level materials--appropriate both to the child's learning level and his/her chronological age.
- Some children may have difficulties with distractibility. Provide a small cubicle, or separate chair behind a screen, to temporarily separate the child from the activities of the surrounding area.

TIPS FOR THE HEALTH PROFESSIONAL WORKING WITH CHILDREN/YOUTH WHO HAVE LEARNING DISABILITIES

Children and youth with learning disabilities may have processing difficulties or mild sensory impairment. Those professionals who work with these children may find it helpful to skim other the other tips sections for more helpful hints.

A. Presenting Information:

- Break tasks into short sequences and present one at a time.
- Give verbal as well as written directions whenever possible.
- Present only one (or few) items or questions at a time during testing and practice periods.
- Include only that material which is absolutely necessary.
- Establish a few realistic goals.
- Keep child's area free from all material except what he/she currently is working with.
- Give the child a longer time than other children to complete tasks.
- Alternate tasks that are difficult and those that are more relaxing.
- Establish a specific schedule so the child knows what to expect; alternate quiet and active times; have short periods of each.
- Keep work periods short; gradually lengthen them as the child begins to cope. Change activities before the child's attention is gone; watch for early signs of attention loss.
- Make movement as purposeful as possible.
- Make certain the child understands directions of assignments, repeating important directions.
- Provide options for obtaining and reporting information --tapes, interviews, reading, experiences, making something, etc.

TIPS FOR THE HEALTH PROFESSIONAL
WORKING WITH CHILDREN/YOUTH WHO HAVE HEARING IMPAIRMENTS

A. Environmental Considerations:

- Arrange the seating so that the child can sit near you and observe your face, as well as others in the room.

- Be aware that gesturing and facial experssions are important cues which help the hearing impaired child's understanding.

- Realize that the child needs to see your full unobstructed face to gain cues. Long hair or a mustache may obstruct the ability to see your face and read lip formations accurately.

- Allow the child to move around to see the speaker.

- Have the child sit with his/her back to the light so the light falls on your face or on the material the child must focus on.

Children/Youth with Hearing Aids:

- If the child wears a hearing aid, consult with a parent, teacher of the hearing impaired, or audiologist for specific information on the operation of the aid. Unless the child ckecks his/her hearing aid, it would be helpful for you to know how to check the aid to see if it is working properly. Specifically:

  1. Check to see if the aid is on.
  2. Check connecting plug for firm connection.
  3. Check for frayed wires.
  4. Have spare batteries and know how to change them.
  5. Check to ensure earmold is properly inserted.

- A child with a hearing aid should be 4 - 10 feet away from the speaker. Remember to use a normal voice; exaggerated speech distorts sounds and lip movements. Speaking too slowly is as ineffective as speaking too rapidly.

- Be aware that aids amplify all sounds including instructional and environmental sounds, such as feet shuffling, paper crumpling, air conditioning, etc.

B. **Other Considerations:**

- Listening skills must be encouraged to help the child maximize any residual hearing; encourage the use of any hearing the child does have. An audiologist can help here.

- Listening is hard work; provide a variety of activities balancing those that require concentrated attention and those that are more natural and thus relaxing for the child.

- If a word has several meanings, explain them. Words like pail or plain, if lip read, look like pale and plane--the child needs to know all meanings so comprehension is increased and confusion decreased.

C. **Materials and Media Considerations:**

- Use a lot of visuals--pictures, models, posters, manipulatives, etc., to supplement your verbal presentations; the old adage, a picture is worth a 1,000 words, is true here.

- When using pictures and models be sure to hold them to the side of your face, not covering your face. Holding them over your chest tends to make you want to look down and talk, thus obscuring your lips from the child's view.

- When presenting instructions, have them available in print as well as giving them verbally.

D. **Presentation Considerations:**

- Organize your presentations into sequential steps. Indicate clearly when you move from step to step.

- If you need to repeat something, try rephrasing it to give more cues. Don't just repeat and repeat the same thing.

- Periodically, summarize what has gone on before proceeding. Ask for confirmation that concepts are understood before going on.

- Make transitions from one topic to another very obvious. Use body movements, and visually hold up the object you are about to discuss.

TIPS FOR THE HEALTH PROFESSIONAL WORKING WITH CHILDREN/YOUTH WHO HAVE VISUAL IMPAIRMENTS

A. Environmental Considerations:

- Seat the child in clear view of the person speaking.
- Seat the child with his/her back to the light.
- If the room arrangment is changed, inform the child and let him/her explore where and how changes were made.
- Keep supplies in the same, predetermined place. This will allow the child greater independence in locating the materials needed.
- Be sure the child knows about the location of any breakable, or potentially harmful objects.
- Half-open or swinging doors can be potentially dangerous; have doors either open or closed.
- Tell the child when you are leaving or entering the room.

B. Other Considerations:

- Most partially sighted children can learn to use their residual sight; encourage the child to do so. Consult with a vision specialist about this.
- Using residual sight may make the child tire easily, as it is hard, concentrated work. Plan varied activities so as not to fatigue the child with one type of visual task.
- When written directions are given, read them aloud giving auditory information.
- Whenever possible, have information on tape--these can be prepared by you, an aide, or a volunteer.
- Assist the child in developing active listening skills.

C. Developing Social Skills:

- Habits such as rocking back and forth, head rolling, or staring at bright lights may have developed because of a need for self-stimulation. To decrease this behavior, it may be helpful to keep the child involved in interesting, manipulative-type tasks. Also, do not hesitate to quietly remind the child of such habits.

D. Material Considerations:

- Use concrete objects and manipulatives to give tactile cues the child can learn from.
- Become familiar with materials such as large print books and cassette tapes available from the State library and your Special Education Regional Resource Center (SERRC). Also, pamphlets containing useful information can be obtained from your local Bureau of Services for the Blind (BSB).

TIPS FOR THE HEALTH PROFESSIONAL WORKING WITH CHILDREN/YOUTH WHO HAVE PHYSICAL OR ORTHOPEDIC HANDICAPS

A. Environmental Considerations:

- Allow room for movement--increase aisles to 60" and more for turning corners.
- Identify or help plan for strategically located ramps, bathrooms, drinking fountains, and curb gradings to increase the child's mobility in and around your facility.
- Be sure there is adequate maneuvering space next to a door.
- Provide ample space near a child's chair or table to store crutches and any other adaptive equipment.
- Doors should not require more than approximately 6-8 pounds of pressure to open (even less for smaller, younger children using wheelchairs). If such doors are a problem for the child, arrange for assistance.
- Make materials available on a level which is comfortable for the child in a wheelchair to reach them.

B. Considerations for Children with Motor Coordination Problems:

- Encourage development of writing skills. Slow and illegible writing should be understood as a motor control problem rather than as an intellectual deficit.
- Let the child take an active role in demonstrating and explaining any adaptive equipment he/she may use.
- Understand that people who sit in wheelchairs for hours at a time may develop problems with circulation and/or sores. To prevent this, they will shift their weight frequently. This is not fidgeting or restleness.
- Provide adequate time to complete a task.
- Be aware that some children may have difficulty in speaking clearly. Your patience is needed here to be understanding and to become familiar with the child's words.

- If spastic or jerking movements are exhibited, understand that the child is not acting out or "behaving strangely" intentionally. These involuntary motions cannot be controlled by the child. Familiarity here will help everyone involved to feel more comfortable.

Appendix 4 A

Chart of Normal Development: Infancy to Six Years of Age

The chart of normal development on the next few pages presents children's achievements from infancy to six years of age in five areas:

- motor skills (gross and fine)
- cognitive skills
- self-help skills
- social skills
- communication skills (understanding language and speaking language).

In each skill area, the age at which each milestone is reached *on the average* is also presented. This information is useful if you have a child in your class who you suspect is seriously delayed in one or more skill areas.

However, it is important to remember that these milestones are only average. From the moment of birth, each child is a distinct individual, and develops in his or her unique manner. No two children have ever reached all the same developmental milestones at the exact same ages. The examples that follow show what we mean.

By nine months of age, Gi Lin had spent much of her time scooting around on her hands and tummy, making no effort to crawl. After about a week of pulling herself up on chairs and table legs, she let go and started to walk on her own. Gi Lin skipped the crawling stage entirely and scarcely said more than a few sounds until she was 15 months old. But she walked with ease and skill by 9½ months.

Marcus learned to crawl on all fours very early, and continued crawling until he was nearly 18 months old, when he started to walk. However, he said single words and used two-word phrases meaningfully before his first birthday. A talking, crawling baby is quite a sight!

Molly worried her parents by saying scarcely a word, although she managed to make her needs known with sounds and gestures. Shortly after her second birthday, Molly suddenly began talking in two- to four-word phrases and sentences. She was never again a quiet child.

All three children were healthy and normal. By the time they were three years old, there were no major differences among them in walking or talking. They had simply developed in their own ways and at their own rates. Some children seem to concentrate on one thing at a time — learning to crawl, to walk, or to talk. Other children develop across areas at a more even rate.

As you read the chart of normal development, remember that children don't read baby books. They don't know they're supposed to be able to point out Daddy when they are a year old, or copy a circle in their third year. And even if they could read the baby books, they probably wouldn't follow them! Age-related development milestones are obtained by averaging out what many children do at various ages. No child is "average" in all areas. Each child is a unique person.

One final word of caution. As children grow, their abilities are shaped by the opportunities they have for learning. For example, although many five-year-olds can repeat songs and rhymes, the child who has not heard songs and rhymes many times cannot be expected to repeat them. All areas of development and learning are influenced by children's experiences as well as by the abilities they are born with.

From: Mainstreaming, Pre-schoolers, Head Start Bureau.

Chart of Normal Development

	Motor Skills		Communication Skills	
	Gross Motor Skills	Fine Motor Skills	Understanding of Language	Spoken Language
0-12 Months	Sits without support. Crawls. Pulls self to standing and stands unaided. Walks with aid. Rolls a ball in imitation of adult.	Reaches, grasps, puts object in mouth. Picks things up with thumb and one finger (pincer grasp). Transfers object from one hand to other hand. Drops and picks up toy.	Responds to speech by looking at speaker. Responds differently to aspects of speaker's voice (for example, friendly or unfriendly, male or female). Turns to source of sound. Responds with gesture to **hi, bye-bye,** and **up,** when these words are accompanied by appropriate gesture. Stops ongoing action when told **no** (when negative is accompanied by appropriate gesture and tone).	Makes crying and non-crying sounds. Repeats some vowel and consonant sounds (babbles) when alone or when spoken to. Interacts with others by vocalizing after adult. Communicates meaning through intonation. Attempts to imitate sounds.
12-24 Months	Walks alone. Walks backward. Picks up toys from floor without falling. Pulls toy, pushes toy. Seats self in child's chair. Walks up and down stairs (hand-held). Moves to music.	Builds tower of 3 small blocks. Puts 4 rings on stick. Places 5 pegs in pegboard. Turns pages 2 or 3 at a time. Scribbles. Turns knobs. Throws small ball. Paints with whole arm movement, shifts hands, makes strokes.	Responds correctly when asked **where,** (when question is accompanied by gesture). Understands prepositions **on, in,** and **under.** Follows request to bring familiar object from another room. Understands simple phrases with key words (for example, **Open the door,** or **Get the ball**). Follows a series of 2 simple but related directions.	Says first meaningful word. Uses single words plus a gesture to ask for objects. Says successive single words to describe an event. Refers to self by name. Uses **my** or **mine** to indicate possession. Has vocabulary of about 50 words for important people, common objects, and the existence, nonexistence, and recurrence of objects and events (for example, **more** and **all gone**).

Cognitive Skills		Self-Help Skills	Social Skills
Follows moving object with eyes. Recognizes differences among people. Responds to strangers by crying or staring. Responds to and imitates facial expressions of others. Responds to very simple directions (for example, raises arms when someone says, **Come,** and turns head when asked, **Where is Daddy?**).	Imitates gestures and actions (for example, shakes head no, plays peek-a-boo, waves bye-bye). Puts small objects in and out of container with intention.	Feeds self cracker. Holds cup with two hands. Drinks with assistance. Holds out arms and legs while being dressed.	Smiles spontaneously. Responds differently to strangers than to familiar people. Pays attention to own name. Responds to **no.** Copies simple actions of others.
Imitates actions and words of adults. Responds to words or commands with appropriate action (for example: **Stop that. Get down**). Is able to match two similar objects. Looks at storybook pictures with an adult, naming or pointing to familiar objects on request (for example: **What is that? Point to the baby**).	Recognizes difference between **you** and **me.** Has very limited attention span. Accomplishes primary learning through own exploration.	Uses spoon, spilling little. Drinks from cup, one hand, unassisted. Chews food. Removes shoes, socks, pants, sweater. Unzips large zipper. Indicates toilet needs.	Recognizes self in mirror or picture. Refers to self by name. Plays by self. Initiates own play. Imitates adult behaviors in play. Helps put things away.

Chart of Normal Development

	Motor Skills		Communication Skills	
	Gross Motor Skills	Fine Motor Skills	Understanding of Language	Spoken Language
24-36 Months	Runs forward well. Jumps in place, two feet together. Stands on one foot, with aid. Walks on tiptoe. Kicks ball forward.	Strings 4 large beads. Turns pages singly. Snips with scissors. Holds crayon with thumb and fingers, not fist. Uses one hand consistently in most activities. Imitates circular, vertical, horizontal strokes. Paints with some wrist action. Makes dots, lines, circular strokes. Rolls, pounds, squeezes, and pulls clay.	Points to pictures of common objects when they are named. Can identify objects when told their use. Understands questions forms **what** and **where.** Understands negatives **no, not, can't,** and **don't.** Enjoys listening to simple storybooks and requests them again.	Joins vocabulary words together in two-word phrases. Gives first and last name. Asks **what** and **where** questions. Makes negative statements (for example, **Can't open it**). Shows frustration at not being understood.
36-48 Months	Runs around obstacles. Walks on a line. Balances on one foot for 5 to 10 seconds. Hops on one foot. Pushes, pulls, steers wheeled toys. Rides (that is, steers and pedals) tricycle. Uses slide without assistance. Jumps over 15 cm. (6") high object, landing on both feet together. Throws ball overhead. Catches ball bounced to him or her.	Builds tower of 9 small blocks. Drives nails and pegs. Copies circle. Imitates cross. Manipulates clay materials (for example, rolls balls, snakes, cookies).	Begins to understand sentences involving time concepts (for example, **We are going to the zoo tomorrow**). Understands size comparatives such as **big** and **bigger.** Understands relationships expressed by **if...then** or **because** sentences. Carries out a series of 2 to 4 related directions. Understands when told, **Let's pretend.**	Talks in sentences of three or more words, which take the form agent-action-object (**I see the ball**) or agent-action-location (**Daddy sit on chair**). Tells about past experiences. Uses "s" on nouns to indicate plurals. Uses "ed" on verbs to indicate past tense. Refers to self using pronouns **I** or **me.** Repeats at least one nursery rhyme and can sing a song. Speech is understandable to strangers, but there are still some sound errors.

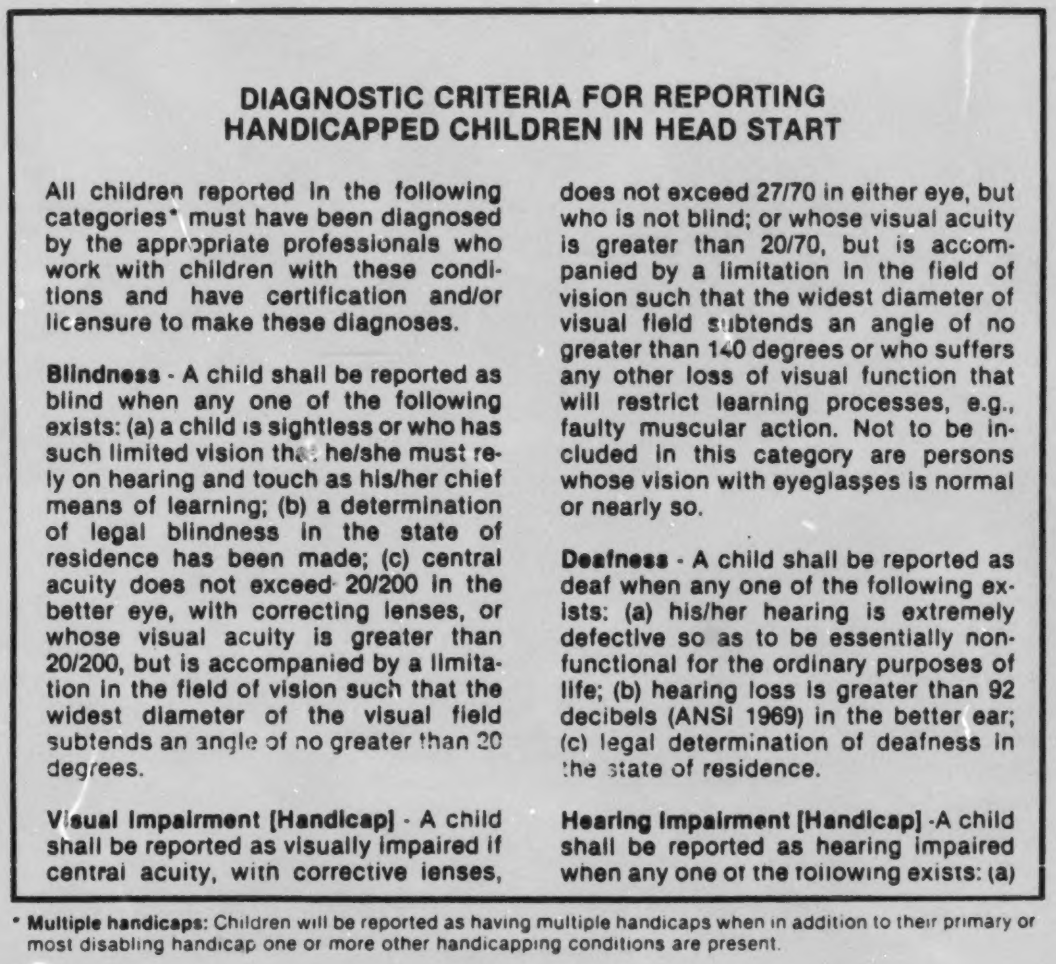
Cognitive Skills		Self-Help Skills	Social Skills
Responds to simple directions (for example: **Give me the ball and the block. Get your shoes and socks**). Selects and looks at picture books, names pictured objects, and identifies several objects within one picture. Matches and uses associated objects meaningfully (for example, given cup, saucer, and bead, puts cup and saucer together). Stacks rings on peg in order of size. Recognizes self in mirror, saying, **baby**, or own name.	Can talk briefly about what he or she is doing. Imitates adult actions (for example, housekeeping play). Has limited attention span. Learning is through exploration and adult direction (as in reading of picture stories). Is beginning to understand functional concepts of familiar objects (for example, that a spoon is used for eating) and part/whole concepts (for example, parts of the body).	Uses spoon, spilling little. Gets drink from fountain or faucet unassisted. Opens door by turning handle. Takes off coat. Puts on coat with assistance. Washes and dries hands with assistance.	Plays near other children. Watches other children, joins briefly in their play. Defends own possessions. Begins to play house. Symbolically uses objects, self in play. Participates in simple group activity (for example, sings, claps, dances). Knows gender identity.
Recognizes and matches six colors. Intentionally stacks blocks or rings in order of size. Draws somewhat recognizable picture that is meaningful to child, if not to adult. Names and briefly explains picture. Asks questions for information (**why** and **how** questions requiring simple answers). Knows own age. Knows own last name.	Has short attention span. Learns through observing and imitating adults, and by adult instruction and explanation. Is very easily distracted. Has increased understanding of concepts of the functions and groupings of objects (for example, can put doll house furniture in correct rooms) part/whole (for example, can identify pictures of hand and foot as parts of body). Begins to be aware of past and present (for example: **Yesterday we went to the park. Today we go to the library**).	Pours well from small pitcher. Spreads soft butter with knife. Buttons and unbuttons large buttons. Washes hands unassisted. Blows nose when reminded. Uses toilet independently.	Joins in play with other children. Begins to interact. Shares toys. Takes turns with assistance. Begins dramatic play, acting out whole scenes (for example, traveling, playing house, pretending to be animals).

Chart of Normal Development

	Motor Skills		Communication Skills	
	Gross Motor Skills	Fine Motor Skills	Understanding of Language	Spoken Language
48-60 Months	Walks backward toe-heel. Jumps forward 10 times, without falling. Walks up and down stairs alone, alternating feet. Turns somersault.	Cuts on line continuously. Copies cross. Copies square. Prints a few capital letters.	Follows three unrelated commands in proper order. Understands comparatives like pretty, prettier, and prettiest. Listens to long stories but often misinterprets the facts. Incorporates verbal directions into play activities. Understands sequencing of events when told them (for example, **First we have to go to the store, then we can make the cake, and tomorrow we will eat it**).	Asks **when, how,** and **why** questions. Uses models like **can, will, shall, should,** and **might.** Joins sentences together (for example, **I like chocolate chip cookies and milk**). Talks about causality by using **because** and **so.** Tells the content of a story but may confuse facts.
60-72 Months	Runs lightly on toes. Walks on balance beam. Can cover 2 meters (6'6") hopping. Skips on alternate feet. Jumps rope. Skates.	Cuts out simple shapes. Copies triangle. Traces diamond. Copies first name. Prints numerals 1 to 5. Colors within lines. Has adult grasp of pencil. Has handedness well established (that is, child is left- or right-handed). Pastes and glues appropriately.	Demonstrates preacademic skills.	There are few obvious differences between child's grammar and adult's grammar. Still needs to learn such things as subject-verb agreement, and some irregular past tense verbs. Can take appropriate turns in a conversation. Gives and receives information. Communicates well with family, friends, or strangers.

Cognitive Skills		Self-Help Skills	Social Skills
Plays with words (creates own rhyming words; says or makes up words having similar sounds). Points to and names 4 to 6 colors. Matches pictures of familiar objects (for example, shoe, sock, foot; apple, orange, banana). Draws a person with 2 to 6 recognizable parts, such as head, arms, legs. Can name or match drawn parts to own body. Draws, names, and describes recognizable picture. Rote counts to 5, imitating adults.	Knows own street and town. Has more extended attention span. Learns through observing and listening to adults as well as through exploration. Is easily distracted. Has increased understanding of concepts of function, time, part/whole relationships. Function or use of objects may be stated in addition to names of objects Time concepts are expanding. The child can talk about yesterday or last week (a long time ago), about today, and about what will happen tomorrow.	Cuts easy foods with a knife (for example, hamburger patty, tomato slice). Laces shoes.	Plays and interacts with other children. Dramatic play is closer to reality, with attention paid to detail, time, and space. Plays dress-up. Shows interest in exploring sex differences.
Retells story from picture book with reasonable accuracy. Names some letters and numerals. Rote counts to 10. Sorts objects by single characteristics (for example, by color, shape, or size. Is beginning to use accurately time concepts of tomorrow and yesterday. Uses classroom tools (such as scissors and paints) meaningfully and purposefully.	Begins to relate clock time to daily schedule. Attention span increases noticeably. Learns through adult instruction. When interested, can ignore distractions. Concepts of function increase as well as understanding of why things happen. Time concepts are expanding into an understanding of the future in terms of major events (for example, Christmas will come after two weekends).	Dresses self completely. Ties bow. Brushes teeth unassisted. Crosses street safely.	Chooses own friend(s). Plays simple table games. Plays competitive games. Engages with other children in cooperative play involving group decisions, role assignments, fair play.

☆ U.S. GOVERNMENT PRINTING OFFICE : 1978 O—270-712



DIAGNOSTIC CRITERIA FOR REPORTING HANDICAPPED CHILDREN IN HEAD START

All children reported in the following categories* must have been diagnosed by the appropriate professionals who work with children with these conditions and have certification and/or licensure to make these diagnoses.

Blindness - A child shall be reported as blind when any one of the following exists: (a) a child is sightless or who has such limited vision that he/she must rely on hearing and touch as his/her chief means of learning; (b) a determination of legal blindness in the state of residence has been made; (c) central acuity does not exceed 20/200 in the better eye, with correcting lenses, or whose visual acuity is greater than 20/200, but is accompanied by a limitation in the field of vision such that the widest diameter of the visual field subtends an angle of no greater than 20 degrees.

Visual Impairment [Handicap] - A child shall be reported as visually impaired if central acuity, with corrective lenses, does not exceed 27/70 in either eye, but who is not blind; or whose visual acuity is greater than 20/70, but is accompanied by a limitation in the field of vision such that the widest diameter of visual field subtends an angle of no greater than 140 degrees or who suffers any other loss of visual function that will restrict learning processes, e.g., faulty muscular action. Not to be included in this category are persons whose vision with eyeglasses is normal or nearly so.

Deafness - A child shall be reported as deaf when any one of the following exists: (a) his/her hearing is extremely defective so as to be essentially non-functional for the ordinary purposes of life; (b) hearing loss is greater than 92 decibels (ANSI 1969) in the better ear; (c) legal determination of deafness in the state of residence.

Hearing Impairment [Handicap] -A child shall be reported as hearing impaired when any one of the following exists: (a) the child has slightly to severely defective hearing, as determined by his/her ability to use residual hearing in daily life, sometimes with the use of a hearing aid; (b) hearing loss from 26-92 decibels (ANSI 1969) in the better ear.

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* **Multiple handicaps:** Children will be reported as having multiple handicaps when in addition to their primary or most disabling handicap one or more other handicapping conditions are present.

From: The Status of Handicapped Children in Head Start Programs, February 1980.

Physical Handicap [Orthopedic Handicap] - A child shall be reported as crippled or with an orthopedic handicap who has a condition which prohibits or impedes normal development of gross or fine motor abilities. Such functioning is impaired as a result of conditions associated with congenital anomalies, accidents, or diseases; these conditions include, for example, spina bifida, loss of or deformed limbs, burns with cause contractures, cerebral palsy.

Speech Impairment [Communication Disorder] - A child shall be reported as speech impaired with such identifiable disorders as receptive and/or expressive language impairment, stuttering, chronic voice disorders, and serious articulation problems affecting social, emotional, and/or educational achievement; and speech and language disorders accompanying conditions of hearing loss, cleft palate, cerebral palsy, mental retardation, emotional disturbance, multiple handicapping condition, and other sensory and health impairments. This category excludes conditions of a transitional nature consequent to the early developmental processes of the child.

Health Impairment - These impairments refer to illness of a chronic nature or with prolonged convalescence including, but not limited to, epilepsy, hemophilia, severe asthma, severe cardiac conditions, severe allergies, blood disorders (e.g., sickle cell disease, hemophilia, leukemia), diabetes, or neurological disorders.

Mental Retardation - A child shall be considered mentally retarded who, during the early developmental period, exhibits significant subaverage intellectual functioning accompanied by impairment in adaptive behavior. In any determination of intellectual functioning using standardized tests that lack adequate norms for all racial/ethnic groups at the preschool age, adequate consideration should be given to cultural influences as well as age and developmental level (i.e., finding of a low I.Q. is *never by itself sufficient* to make the diagnosis of mental retardation).

Serious Emotional Disturbance - A child shall be considered seriously emotionally disturbed who is identified by professionally qualified personnel (psychologist or psychiatrist) as requiring special services. This definition would include but not be limited to the following conditions: dangerously aggressive towards others, self-destructive, severely withdrawn and non-communicative, hyperactive to the extent that it affects adaptive behavior, severely anxious, depressed or phobic, psychotic or autistic.

Specific Learning Disabilities - Children who have a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. Such disorders include such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. Such term does not include children who have learning problems which are primarily the result of visual, hearing, or motor handicaps, of mental retardation, of emotional disturbance, or of environmental disadvantage. For preschool children, *precursor functions* to understanding and using language spoken or written, and computational or reasoning abilities are included. (Professionals considered qualified to make this diagnosis are physicians and psychologists with evidence of special training in the diagnosis of learning disabilities and at least Master's degree level special educators with evidence of special training in the diagnosis of learning disabilities.)

Appendix 4B
Sample "Screening" Questions for Various Developmental Levels from Pregnancy To 8 Years of Age*

(A) PREGNANCY

Examples of Questions	Illustration of "At Risk" Response
1. How often do you visit with your parents or other family?	1. Rarely
2. Has anything happened either before or during your pregnancy that causes you to worry about the baby?	2. My husband calls his ex-wife all the time. It upsets me terribly. I'm afraid it will hurt the baby.
3. Do you have any condition that you think might be made worse by being pregnant?	3. Yes, I had a kidney infection last year.
4. What was your reaction when you felt life?	4. I don't remember.
5. Is your husband (the father of the child) much help?	5. He's like another child to take care of.
6. How would you compare the way you feel now with the way you normally feel?	6. Everything hurts. Can't get my housework done. Never sleep now.

(B) NEONATAL PERIOD (up to 4 weeks)

Examples of Questions	Illustration of "At Risk" Response
1. Do you think you can tell your baby's cry from others?	1. No. They all sound the same to m
2. How does the baby compare with what you imagined he/she would be like when you were pregnant?	2. Very different. He's too active. Never gives me any peace. And he doesn't look like either of us Wonder if it's mine.
3. As far as you know, is everything OK with the baby?	3. The doctor told me he was fine. But my girl friend lost her baby when he was 4 months old. Maybe something will happen.

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* Developed by Richard L. Cohen, M.D., University of Pittsburgh, Western Psychiatric Institute and Clinic, School of Medicine, Department of Psychiatr Division of Child Psychiatry.

4. Are you getting any help with the baby?	4. I'd rather not. I really don't trust anyone else with him.
5. How has your husband (mate) reacted to the baby?	5. I think he's pretty jealous of him.
6. Are you satisfied with your ability to take care of the baby?	6. He's really a mystery to me. I never know what he wants. He keeps me running in circles.

(C) LATER INFANCY (up to 15 or 18 months)

Examples of Questions	Illustration of "At Risk" Response
1. Does the baby seem to know you? How can you tell? (around 4 months)	1. I'm not sure. He smiles at me, but he smiles at everybody the same way.
2. What does the baby seem to be interested in? (around 6 months)	2. He's pretty quiet. He mostly likes to look at the TV.
3. What does he do when a stranger comes into the room? (about 8 months)	3. Anyone can pick him up. He really doesn't seem to favor anybody very much.
4. Does the baby like to explore things? (about 1 year)	4. Yes, but I'm afraid he'll hurt himself. I've got most things put away and I keep him always in the kitchen or his own room.
5. Does the baby try to get your attention by other ways than crying or try to do things with you?	5. No. not really very often.
6. Has he become fairly regular in his habits of eating, sleeping, elimination, etc.?	6. No. Depends entirely on his mood—or maybe mine. I never know what the day will be like.

(D) TODDLERHOOD

Examples of Questions	Illustration of "At Risk" Response
1. What kind of toys does he seem to like to play with?	1. Well, he doesn't really have any of his ow-. He just uses his older brother's who is six.
2. Will he try to ask for things when he wants something?	2. No. He points or cries.

3. What kinds of things can the baby do for himself? For instance, how well can he feed himself?	3. Oh, I don't think kids can be expected to do much at this age. Besides, he makes such a mess, it's simpler for me to do it.
4. Does he seem to say "no" a lot? How do you handle that?	4. I just can't please him. Everything I do is wrong. Maybe he'll go through the rest of his life just rebelling against everything.
5. How does he act if other kids his age are around?	5. He usually ignores them completely.
6. How does he act if you and your husband go out in the evening?	6. He makes a real fuss. The sitter says it takes hours for him to quiet down. I guess I'm thinking about him the whole time we're out.

(E) PRESCHOOL YEARS

Examples of Questions	Illustration of "At Risk" Response
1. What kinds of things do you still have to do for him?	1. He comes to me for almost everything. He still wants me or my husband to go to the bathroom with him.
2. How does he act with kids his own age?	2. He can't share. Always has to be the boss or he won't play.
3. Does he(she) like to imitate father (mother)?	3. No, I can't think of any examples of that.
4. Does he mostly sleep through the night?	4. No. He gets up a lot. He seems to have nightmares. Or he will w the bed and then want to sleep wit us.
5. Is he showing interest in his own body -- and in his parents or siblings?	5. Mostly, he's afraid of getting hur If he falls or cuts himself, he cr a lot and asks a lot of questions about whether it will get well ag
6. What is he interested in? Does he ask lots of questions or want stories to be read to him?	6. He still likes to play with his baby toys. He avoids new things or new ideas. He really wants things to stay the same.

(F) 6 TO 8 YEAR PERIOD

Examples of Questions	Illustration of "At Risk" Response
1. How has he taken to the idea of going to school everyday?	1. He complains and fusses a lot. Full of excuses. We have to stay on top of him the whole time.
2. Does he like to play games with other kids?	2. Yes, but they don't last very long. He likes to change the rules if he's losing and they get angry with him.
3. What does he(she) talk about being when he(she) grows up?	3. We never hear him talk about anything like that. I think he has the idea that he's going to stay with us forever.
4. What is he like when he gets sick?	4. You never saw a bigger baby. He acts like a 2 year old.
5. How does he act toward the baby?	5. He's very jealous. We have to watch him to make sure he doesn't hurt the baby.
6. How does he react to doing chores around the house?	6. We've stopped that. You have to nag so much that it's easier for us to do it.

APPENDIX 5A

NATIONAL OFFICES OF FEDERAL AGENCIES AND PROGRAMS

Child Abuse and Neglect Prevention and Treatment

National Center for Child Abuse and Neglect (NCCAN)
U.S. Department of Health and Human Services
Administration for Children, Youth and Families
Children's Bureau
400 6th Street, S.W.
Washington, D.C. 20013
(202) 245-2856

NCCAN provides information, research, training, technical assistance, and grants and contracts aimed at preventing, identifying, and treating child abuse and neglect. Individuals can contact the national center or the child abuse and neglect specialist located in the regional office of the Department of Health and Human Services.

Child Welfare Services

Children's Bureau
Administration for Children, Youth and Families
P.O. Box 1182
Washington, D.C. 20013
(202) 755-8888

This program delivers services to people in need regardless of income. Services available differ from state to state and may include: foster care and adoption, child care (in-home and out-of-home day care), services to unmarried parents and their babies, homemaker services, protective services, legal services and emergency assistance services. The Social Services Program (Title XX) provides services to persons receiving financial assistance. Families interested in the Child Welfare or the Social Services Programs should apply to the local welfare department or the human resources or social services agency.

Community Mental Health Centers (CMHC)

U.S. Department of Health and Human Services
National Institute of Mental Health
5600 Fishers Lane
Rockville, MD 20857
(301) 443-3606

CMHCs provide comprehensive mental health services including: inpatient, outpatient, day-care, partial hospitalization and emergency services; special services for children and the elderly; consultation and education; and follow-up care for patients discharged from a state mental health facility. Contact the local CMHC or state department of mental health, social services or human services to locate the nearest CMHC.

Crippled Children's Services

U.S. Department of Health and Human Services
Division of Maternal and Child Health
Bureau of Health Care Delivery and Assistance
Room 6-05
5600 Fishers Lane
Rockville, MD 20857
(301) 443-2170

Children and youth below the age of 21 with handicapping (crippling) conditions are eligible for screening, diagnosis and treatment services under this program. Diagnostic services must be provided at no cost to the child or family. Transportation, drugs, therapy, and supplies and equipment also may be provided, depending on the state. Other services are available to SSI recipients. Contact the local Health Department, public health nurse, or Crippled Children's Agency for more information.

Developmental Disabilities - Basic Support

U.S. Department of Health and Human Services
Administration on Developmental Disabilities
Office of Human Development Services
Hubert Humphrey Building - Room 336E
200 Independence Avenue, S.W.
Washington, D.C. 20201
(202) 245-2890

This program encourages coordinated and comprehensive service delivery for persons with developmental disabilities. Services include case management services, child development services, alternative community living arrangements, diagnostic services, counseling, recreation, transportation, employment, training and domiciliary care. Contact the Developmental Disabilities State Planning Council located in the state capitol or the governor's office to find out the state agency designated as responsible for the Developmental Disabilities program.

Educational Resources Information Center (ERIC)

ERIC Clearinghouse on the Handicapped
The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
(703) 620-3660

ERIC maintains computerized information on programs, research and development efforts, publications and related information that can be used in developing more effective education programs. Computer searches, bibliographies and special reports and responses to educational information requests are provided among the services.

Genetic Diseases Testing and Counseling

U.S. Department of Health and Human Services
Bureau of Community Health Services
Parklawn Building - Room 6-49
5600 Fishers Lane
Rockville, MD 20857
(301) 443-1440

This program provides screening, diagnosis, counseling, and referral services for individuals at risk of having or transmitting genetic disorders. Funds can be used to transport patients to the facility if necessary. Contact the local health department to find out where to go for testing or counseling.

Head Start

Head Start
National Office
Administration for Children, Youth and Families
Office of Human Development Services
P.O. Box 1182
Washington, D.C. 20013

The purpose of Head Start is to provide comprehensive services to low-income and handicapped preschool children. This program awards grants to provide services to preschool children and their families in the following areas: health, education, nutrition, social, and other services as required. A major emphasis is to involve parents to the degree that overall gains in the above-mentioned areas are maintained. Parents or others who wish information on Head Start Projects in their area or are interested in initiating a project should contact their neighborbood elementary school.

Information and Referral Services

Clearinghouse on the Handicapped
Office of Information and Resources for the Handicapped
Office of Special Education and Rehabilitative Services
U.S. Department of Education
330 "C" Street, S.W.
Washington, D.C. 20201
(202) 245-0080

This Clearinghouse provides information and referral services regarding federal funding for the handicapped, publications, programs, organizations and other national resources and related services for persons with handicapping conditions.

Maternal and Child Health Services

U.S. Department of Health and Human Services
Health Services Administration
Bureau of Community Health Services
Office of Maternal and Child Health
Rockville, MD 20857
(301) 443-2170

The purpose of this program is to reduce infant mortality and the incidence of handicapping conditions, and improve the health of mothers and children, especially in rural and economically depressed areas, and the condition of infants and children with handicapping conditions. Services are delivered to individuals through local health departments.

Medicaid/Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program

U.S. Department of Health and Human Services
Health Care Financing Administration
Bureau of Program Operations
Child Health and Prevention Staff
6325 Security Blvd.
Meadows East Building, 1F3
Baltimore, MD 21207
(301) 597-1155

This program identifies health problems facing children and youth through age 21. All detected health problems must receive treatment under the Medicaid program or be referred to providers other than Medicaid. Individuals should contact their local health department or the local social services or welfare office to apply for EPSDT services. Other screening services are offered under the Crippled Children's Service Programs.

Medicaid - Title XIX

U.S. Department of Health and Human Services
Health Care Financing Administration
Humphrey Building - Room 414G
200 Independence Avenue, S.W.
Washington, D.C. 20201
(202) 245-6726

Medicaid pays for a variety of health care services of people receiving federal cash assistance and of low income earners who are unable to meet their families medical needs. Children with disabilities may qualify for assistance regardless of their family income. Contact the state welfare or health agency administering Medicaid.

Office for Civil Rights

U.S. Department of Education
Office for Civil Rights
Switzer Building - Room 5430
300 "C" Street, N.W.
Washington, D.C. 20201
(202) 245-8835

The Office for Civil Rights (OCR) is the federal agency responsible for enforcing Section 504. Complaints should be filed with OCR if there are systematic violations of the law in the state or school district that affect a number of children. OCR has regional offices in Boston, New York, Philadelphia, Atlanta, Chicago, Dallas, Kansas City, Denver, San Francisco and Seattle.

Special Education

U.S. Department of Education
Office of Special Education and Rehabilitation Services
Special Education Programs
400 Maryland Avenue, S.W.
Washington, D.C. 20202
(202) 245-9661

Special Education Programs (SEP) is the federal agency responsible for administering P.L. 94-142 and other programs within the Education of the Handicapped Act including early childhood programs, programs for deaf/blind and severely handicapped persons, vocational and adult programs, media and captioned films, among others. Each state employs a State Director of Special Education whose office is located within the state Department of Education in each state capitol (See listing in Unit 1). A local Director of Special Education is employed by most school districts.

Title XX - Social Services Block Grant

Department of Health and Human Services
Office of Human Development Services
Grants and Contracts Management Division
300 Independence Avenue, S.W. - Room 1296
Washington, D.C. 20201
(202) 245-7220

Due to the flexibility of the block grant regulations, there is great diversity among the states regarding available services under this program. Examples include: child day care, counseling, emergency shelter, family planning, foster care, health education, home-delivered meals, homemaker services, information and referral, legal services, nutrition services, protective services, respite care, training and transportation. Apply to the local public welfare agency.

Vocational Education

Divison of Vocational Education Services
Office of Vocational and Adult Education
U.S. Department of Education
Room 5636-C, ROB 3
400 Maryland Avenue, S.W.
Washington, D.C. 20202
(202) 472-3440

This program provides education and training for employment. Ten percent of federal funds must be used for programs for persons with handicapping conditions. For information, contact the local Superintendent of Public Schools.

Vocational Rehabilitation

U.S. Department of Education
Office of Specia Education and Rehabilitation Services
Rehabilitation Services Program
MES Building - Room 3090
330 "C" Street, S.W.
Washington, D.C. 20202
(202) 245-2201

This agency administers the federal Vocational Rehabilitation Act. Each state also employs a State Director of Vocational Rehabilitation within the state government.

NATIONAL ORGANIZATION CONCERNED WITH PEOPLE WITH DISABILITIES

AUTISM

National Society for
Autistic Children
1234 Massachusetts Avenue, N.W.
Suite 1017
Washington, D.C. 20005

CEREBRAL PALSY

United Cerebral Palsy Association
66 East 34th Street, 3rd Floor
New York, New York 10016

DEAF-BLIND

National Association of the Deaf-Blind
2703 Forest Oak Circle
Norman, Oklahoma 73071

EMOTIONALLY DISTURBED

Mental Health Association,
National Headquarters
1800 North Kent Street
Arlington, Virginia 22209
(703) 528-6405

The National Alliance for the
Mentally Ill
1234 Massachusetts Avenue, N.W.
Suite 721
Washington, D.C. 20005

National Association of State
Mental Health Program Directors
1001 3rd Street, S.W.
Room 113
Washington, D.C. 20024
(202) 554-7807

EPILEPSY

Epilepsy Foundation of America
1828 L Street, N.W., Suite 406
Washington, D.C. 20036
(202) 293-2930

HEALTH IMPAIRMENTS

American Cancer Society
777 Third Avenue
New York, New York 10017

American Diabetes Association
600 Fifth Avenue
New York, New York 10020

American Heart Association
7320 Greenville Avenue
Dallas, Texas 75231

American Lung Association
1740 Broadway
New York, New York 10019

Asthma and Allergy Foundation
of America
19 West 44th Street
Suite 702
New York, New York 10036

The Candlelighters Foundation
123 C Street, S.E.
Washington, D.C. 20003

Cystic Fibrosis Foundation
3384 Peachtree Road, N.E.
Suite 875
Atlanta, Georgia 30326

Juvenile Diabetes Foundation
23 East 26th Street, 4th Floor
New York, New York 10010

Leukemia Society of America
800 Second Avenue
New York, New York 10017

National Association for
Sickle Cell Disease, Inc.
3460 Wilshire, Suite 1012
Los Angeles, California 90010

National Hemophilia Foundation
19 West 34th Street, Room 1204
New York, New York 10001

HEALTH IMPAIRMENTS (cont)

National Kidney Foundation
Two Park Avenue
New York, New York 10016

National Neurofibromatosis
Foundation
340 East 80th Street, #21-H
New York, New York 10021

National Tay-Sachs Foundation
and Allied Diseases Association
122 East 42nd Street
New York, New York 10017

National Tuberous Sclerosis
Association, Inc.
P.O. Box 159
Laguna Beach, California 92652

United Ostomy Association
2001 W. Beverly Boulevard
Los Angeles, California 90057

HEARING IMPAIRED

Alexander Graham Bell Association
for the Deaf
3417 Volta Place, N.W.
Washington, D.C. 20007

National Association of
the Deaf
814 Thayer Avenue
Silver Spring, Maryland 20910
(301) 587-1788

National Center for Law and
the Deaf, Gallaudet College
7th Street and Florida Avenue, N.E.
Washington, D.C. 20002

Registry of Interpreters for
the Deaf, Inc.
814 Thayer Avenue
Silver Spring, Maryland 20910

LEARNING DISABILITIES

Association for Children and
Adults with Learning Disabilities
4156 Library Road
Pittsburgh, Pennsylvania 15234
(412) 341-1515

The Orton Society, Inc.
8415 Bellona Lane
Suite 115
Towson, Maryland 21204

National Network of Learning
Disabled Adults
P.O. Box 3130
Richardson, Texas 75080

MENTAL RETARDATION

American Association of
Mental Deficiency
5101 Wisconsin Avenue, N.W.
Suite 405
Washington, D.C. 20016
(202) 686-5400

Association for Retarded Citizens
2709 Avenue E. East
P.O. Box 6109
Arlington, Texas 76011
(817) 640-0204

Down's Syndrome Congress
1640 W. Roosevelt Road
Room 156E
Chicago, Illinois 60608

National Association of
Coordinators of State
Programs for the Mentally
Retarded
2001 Jefferson Davis Hwy.
Suite 806
Arlington, Virginia 22202
(703) 920-0700

MENTAL RETARDATION (cont)

National Association of
Private Residential Facilities
for the Mentally Retarded
6269 Leesburg Pike, Suite B-5
Arlington, Virginia 22044
(703) 536-3311

President's Committee on
Mental Retardation
Regional Office Building
7th and D Street, S.W.
Washington, D.C. 20201
(202) 245-7596

PHYSICALLY HANDICAPPED

American Brittle Bone Society
Cherry Hill Plaza Suite LL-3
1415 East Marlton Pike
Cherry Hill, New Jersey 08034

American Physical Therapy
Association
1156 15th Street, N.W.
Washington, D.C. 20005
(202) 466-2070

Arthritis Foundation
3400 Peachtree Road, N.E.
Suite 1106
Atlanta, Georgia 30326

Human Growth Foundation
4930 West 77th Street
Minneapolis, Minnesota 55435

Little People of America
P.O. Box 126
Owatonna, Minnesota 55060

Muscular Dystrophy Association, Inc.
810 Seventh Avenue
New York, New York 10019
(212) 586-0808

National Amputation Foundation
12-45 150th Street
Whitestone, New York 11357

PHYSICALLY HANDICAPPED (cont)

The National Association of
the Physically Handicapped, Inc.
76 Elm Street
London, Ohio 43140

National Multiple Sclerosis
Society
205 East 42nd Street
New York, New York 10017

National Spinal Cord Injury
Foundation
369 Elliot Street
Newton Upper Falls, Massachusetts 021

Osteogenesis Imperfecta Foundation
632 Center Street
Van Wert, Ohio 45891

Spina Bifida Association
of America
343 South Dearborn Street
Room 319
Chicago, Illinois 60604

Tourette Syndrome Association
40-08 Corporal Kennedy Street
Bayside, New York 11361

SPEECH IMPAIRMENTS

American Speech - Language -
Hearing Association
10801 Rockville Pike
Rockville, Maryland 20852
(301) 897-5700

VISUAL IMPAIRMENTS

American Council of the Blind
1211 Connecticut Avenue
Suite 506
Washington, D.C. 20036

American Council of the
Blind Parents
Rt. A Box 78
Franklin, Louisiana 70538

VISUAL IMPARIMENTS (cont)

American Foundation for the Blind
15 West 16th Street
New York, New York 10011

Council of Citizens with Low Vision
1211 Connecticut Avenue, N.W.
Washington, D.C. 20036

International Institute for Visually Impaired 0-7, Inc.
1975 Rutgers Circle
East Lansing, Michigan 48823

National Association of Blind Students
1211 Connecticut Avenue, N.W.
Suite 506
Washington, D.C. 20036

National Association for Parents of Visually Impaired
2011 Hardy Circle
Austin, Texas 78757

National Association for the Visually Handicapped
305 East 24th Street
New York, New York 10010

National Federation of the Blind
1800 Johnson Street
Baltimore, Maryland 21230

ALL DISABILITIES

Accessibility Information Center, National Center for a Barrier Free Environment
1140 Connecticut Avenue, N.W.
Washington, D.C. 20036
(202) 466-6846

American Alliance for Health, Physical Education, Recreation and Dance
1900 Association Drive
Reston, Virginia 22091
(703) 476-3400

ALL DISABILITIES (cont)

American Association of University Affiliated Programs (AAUAP) for the Developmentally Disabled
1234 Massachusetts Avenue, N.W.
Suite 813
Washington, D.C. 20005
(202) 737-1511

American Coalition for Citizens with Disabilities
1200 15th Street, N.W.
Suite 201
Washington, D.C. 20005

American Congress on Rehabilitation Medicine
c/o White, Fine and Verville
1156 15th Street, N.W.
Suite 302
Washington, D.C. 20005
(202) 659-2900

American Occupational Therapy Association
1383 Piccard Dr. Suite 300
Rockville, Maryland 20850
(301) 948-9626

Architectural and Transportation Barriers Compliance Board (ATBCB)
Office of Public Information
Washington, D.C. 20201
(202) 245-1591

The Association for the Severely Handicapped
1600 West Armory Way
Garden View Suite
Seattle, Washington 98119

Children's Defense Fund
1520 New Hampshire Avenue, N.W.
Washington, D.C. 20036
(202) 628-8787

Closer Look
c/o Parent's Campaign for Handicapped Children and Youth
1201 16th Street, N.W. Suite 233
Washington, D.C. 20036
(202) 822-7900

ALL DISABILITIES (cont)

The Council for Exceptional Children
1920 Association Dr.
Reston, Virginia 22091
(703) 620-3660

Council for State Administrators
of Vocational Rehabilitation
1522 K Street, N.W.
Washington, D.C. 20005

Higher Education and the Handicapped
(HEATH) Project of American Council
on Education
One Dupont Circle, Suite 20
Washington, D.C. 20036

Joseph P. Kennedy, Jr.
Foundation
1701 K Street, N.W.
Suite 205
Washington, D.C. 20006
(202) 331-1731

March of Dimes Birth Defect
Foundation
1275 Mamaroneck Avenue
White Plains, New York 10605

National Association for
Students with Handicaps
Iowa Memorial Union
University of Iowa
Iowa City, Iowa 52240

National Arts and The
Handicapped Information
Service, National
Endowment for the Arts
2401 E Street, N.W.
Washington, D.C. 20506

ALL DISABILITIES (cont)

National Easter Seal Society
2023 W. Ogden Avenue
Chicago, Illinois 60612
(312) 243-8400

People First International, Inc.
P.O. Box 12642
Salem, Orgeon 97309
(503) 378-5143

President's Committee on
Employment of the
Handicapped
1111 20th Street, N.W.
Washington, D.C. 20036
(202) 653-5044

Regional Rehabilitation Research
Institute on Attitudinal,
Legal, and Leisure Barriers
George Washington University,
Barrier Awareness Project,
1828 L Street, N.W.
Washington, D.C. 20036

Appendix 5C

REFERRAL FORM

Date ______________ From ________________________ (Name)

To ________________________ (Agency)

________________________ (Agency)

Atten ________________________

________________________ (Address)

________________________ (Telephone)

Child's Name ____

Child's Sex ________________ Child's DOB ________________

Reasons for Referral/Service Desired ________________________

____

____

____

Test Results, Observed Behavior, Professional Concerns ________

____

____

____

____

____

Signature ________________________

Position ________________________

Appendix 5D

RELEASE FORM

Date ______________________________

TO WHOM IT MAY CONCERN:

This is to authorize ____

to forward all records concerning testing, academic performance, health information and diagnosis, psychological evaluations and other information as listed, ____

____

____

____

for my child ____

These records are to be sent to: _____________________________________

____

____

____

____

Signature of Parent or Guardian

Appendix 5E

SAMPLE FORM C(1)

AGENCY REFERRAL AND FOLLOW-UP LOG
Step 1
REFERRAL PROCESS

RECIPIENT	AGENCY AND CONTACT PERSON	SERVICE REQUESTED	REFERRAL METHOD	REFERRAL DATE	COMMENTS

AGENCY REFERRAL AND FOLLOW-UP LOG
Step 2
FOLLOW-UP PROCESS

RECIPIENT	AGENCY	DATE OF INITIAL CONTACT	NO. OF DAYS TO CONTACT	DATE OF SERVICE DELIVERY	NO. OF DAYS TO DELIVERY	COMMENTS OR QUALITY OF SERVICE

Appendix 5E

SAMPLE FORM C(2)

Appendix 5F

AGENCY RESPONSE FORM

Date: ____________________

TO: ____________________ (Name of Agency and Contact)

FROM: ____________________ (Health Practitioner)

RE: ____________________ ____________________

Client's Name Services Requested

As stated in the enclosed referral form, I am referring ____________

____________ for ____________________.

I feel that this child needs immediate attention and hope you will be able to make an initial contact/intake appointment within ten (10) days. Please return the bottom portion of this form for our records. Thank you.

Return to ____________________

____

____

____

Client: ____________________

Date of Initial Contact/Intake Appointment: ____________________

Services Rendered and Dates of Service Delivery: ____________________

____

____

Date ____________ Signed ____________________

Agency ____________________

Appendix 6A

ADMINISTRATION ON DEVELOPMENTAL DISABILITIES
STATE PROTECTION AND ADVOCACY AGENCIES

ALABAMA
Kathryn Harwood, Program Director
Alabama DD Advocacy Program
918 4th Avenue
Tuscaloosa, Alabama 35401
(205) 348-4928

ALASKA
David Maltman, Director
P&A for the Developmentally Disabled,
Inc., 325 E. 3rd. Ave., 2nd Fl.
Anchorage, Alaska 99501
(907) 274-3658
ZENITH 6600 (Statewide toll free)

ARIZONA
Sandra Peel, P&A Program Director
Arizona Center for Law in the
Public Interest
112 North Fifth Ave.
Phoenix, Arizona 85003

ARKNASAS
James C. Hudson, Director
Advocacy Services, Inc.
12th & Marshall Streets, Suite 504
Little Rock, Arkansas 72202
(501) 371-2171

CALIFORNIA
Al Zonca, Executive Director
Protection & Advocacy, Inc.
2131 Capitol Ave., Suite 100
Sacramento, California 95816
(916) 447-3331
(800) 952-5746
L.A. Office (213) 383-7285

COLORADO
Mary Ann Harvey, Executive Director
Legal Center for Handicapped Citizens
1060 Bannock Street, Suite 316
Denver, Colorado 80204
(303) 573-0542

CONNECTICUT
Eliot J. Dober, Executive Director
Office of P&A for Handicapped & DD
Persons
401 Trumbull Street
Hartford, Connecticut 06103
(203) 566-7616
(203) 566-2102 (teletype)
(800) 842-7303 (Statewide toll free)

DELAWARE
Mary McDonough, Executive Director
DD Protection and Advocacy System
913 Washington Street
Wilimington, Delware 19801
(302) 575-0660
(800) 292-7980

DISTRICT OF COLUMBIA
Yetta W. Galiber, Executive Director
Information Center for Handicapped
Individuals
605 G Street, N.W.
Washington, D.C. 20001
(202) 347-4986

FLORIDA
Johnathan P. Rossman, Director
Governor's Commission on Advocacy
for Persons with DD,
Office of the Governor, the Capitol
Tallahassee, Florida 32301
(904) 488-9070

GEORGIA
Donald G. Trites Executive Director
Georgia Advocacy Office, Inc.
1447 Peachtree Street, N.E.
Suite 811
Atlanta, Georgia 30309
(404) 885-1447
(800) 282-4538

GUAM

Martin DeLeon Guerrero, Director
The Advocacy Coordinating Office
for the Developmentally Disabled
P.O. Box 83]9
507 10th Street, 8th Floor
Tamuning, Guam 96911
(011)-(641) 477-7280

HAWAII

Patty Henderson, Executive Director
Kahua Ho'omalu Kina, Inc.
1580 Makaloa Street
Suite 860
Honolulu, Hawaii 96814
(808) 949-2922
EPO 7777 (toll free)

IDAHO

Brent Marchbanks, Director
Idaho's Coalition of Advocates for
the Disabled, Inc.
1510 W. Washington
Boise, Idaho 83702
(208) 336-5353
(800) 632-5125 (toll free)

ILLINOIS

Zena Naiditch, Director
DD P&A Board
180 N. La Salle, Suite 321
Chicago, Illinois 60601
(312) 793-3536

INDIANA

Genevieve R. Riley, Director
Indiana P&A Service Commission for the
Developmentally Disabled
445 N. Pennsylvania St., Room 503
Indianapolis, Indiana 46204
(317) 232-1150
(800) 622-4345

IOWA

Jeanne Porter, Director
Protection and Advocacy Division
Iowa Civil Rights Commission
507 10th Street, 8th Floor
Des Moines, Iowa 50319
(515) 281-8081
(800) 532-1465

KANSAS

Joan Strickler, Executive Director
Kansas Advocacy & Protection Services
for the DD, Inc., The Denholm Bldg.
513 Leavenworth, Suite 2
Manhattan, Kansas 66502
(913) 776-1541
(800) 432-8276

KENTUCKY

Gayla Keown, Director
Office for Public Advocacy
Division for P&A
State Office Bldg. Annex, 2nd Fl.
Frankfort, Kentucky 40601
(502) 564-2967
(800) 372-7705

LOUISIANA

Lois V. Simpson, Director
Advocate for the Developmentally
Disabled
333 St. Charles Ave., Rm. 1221
New Orleans, Louisiana 70130
(504) 522-2337
(800) 662-7705

MAINE

Dean Crocker, Director
Advocates for the DD
Cleveland Hall, Winthrop Street
P.O. Box 88 Hallowell, ME 04347
(207) 289-2395
(800) 452-1948
(207) 289-2394 (Augusta area)

MARYLAND

David Chavkin, Director
Maryland Advocacy Unit for DD (MAUDD)
2510 St. Paul Street
Balitmore, Maryland 21218
(301) 383-3400

MASSACHUSETTS

William Crane, Project Director
DD Law Center for Massachusetts
294 Washington Street, Suite 840
Boston, Massachusetts 02108
(617) 426-7020

MICHIGAN
Elizabeth W. Bauer, Executive Director
Michigan P&A Service for DD Citizens
313 South Washington Square, Lower Level
Lansing, Michigan 48933
(517) 487-1755

MINNESOTA
Luther Granquist, Director
Legal Aid Society of Minneapolis
222 Grain Exchange Building
323 Fourth Avenue, South
Minneapolis, Minnesota 55415
(612) 338-0968

MISSISSIPPI
Becky Floyd, Director
Mississippi P&A System for DD
4750 McWillie Dr., Suite 101
Jackson, Mississippi 65101
(601) 981-8207

MISSOURI
C. Richard Heiser, Jr., Director
Missouri DD P&A Service, Inc.
211 B Metro Drive
Jefferson City, Missouri 65101

(314) 893-3333
(800) 392-8667

MONTANA
Margaret Ulvestad, Executive Director
DD/Montana Advocacy Program, Inc.
1219 East 8th Avenue
Helena, Montana 59601
(406) 449-3889
(800) 332-6149

NEBRASKA
Timothy Shaw, Executive Director
Nebraska Advocacy Services for
DD Citizens, Inc.
Lincoln Ctr. Bldg.
215 Centennial Mall So. Rm. 422
Lincoln, Nebraska 68504
(402) 474-3183

NEVADA
Holli Elder, Project Director
DD Advocate's Office
495 Apple Street
Reno, Nevada 89502
(702) 784-6375
(800) 992-5715
FTS 470-5911 (800) 852-3336

NEW HAMPSHIRE
Donna Woodfin, Director
DD Advocacy Center, Inc.
6 White Street
P.O. Box 19
Concord, New Hampshire 03301
(603) 228-0432

NEW JERSEY
Herbert Hinkle, Director
N.J. Dept. of Public Advocate
Office of Advocacy for the DD
CN 850
Trenton, New Jersey 08625
(609) 292-9742
(800) 792-8600

NEW MEXICO
Jim Jackson, Director
P&A System for New Mexicans
with DD
Suite 300
510 Second Street, N.W.
Albuquerque, NM 87102
(505) 243-8831
(800) 432-4682

NEW YORK
Clarence J. Sundram, Commissioner
NY Commission on Quality of
Care for the Mentally Disabled
99 Washington Avenue
Albany, New York 12210
(518) 474-3183

NORTH CAROLINA
Lockhart Follin-Mace, Director
Governor's Advocacy Council for
Persons with Disabilities
116 West Jones Street
Raleigh, North Carolina 27611
(919) 733-9250

NORTH DAKOTA
Barbara C. Braun, Project Director
P&A Project for the DD
Governor's Council on Human Resources
State Capitol Annex, 1st Floor
Bismarck, North Dakota 58505
(701) 224-2972
(800) 472-2670

OHIO
Pamela Hyde
Executive Director
Ohio Legal Rights Service
8 East Long Street, 6th Floor
Columbus, Ohio 43215
(614) 466-7264
(800) 282-9181

OKLAHOMA
Dr. Bob M. Van Osdol
Director
Protection and Advocacy Agency
for DD
9726 East 42nd
Osage Building, Room 133
Tulsa, Oklahoma 74145
(918) 664-5883

OREGON
Steve Brischetto, Executive Director
Oregon DD Advocacy Center
621 S.W. Morrison, Rm. 713
Portland, Oregon 97205
(503) 243-2081
(800) 452-1694

PENNSYLVANIA
Edwin Frownfelter, Executive Director
DD Advocacy Network (DDAN), Inc.
3540 N. Progress Avenue
Harrisburg, Pennsylvania 17110
(717) 657-3320
(800) 692-7443

PUERTO RICO
Juan Rivera, Director
Protection and Advocacy
Puerto Rico Dept. od Consumer Affairs,
Minillas Governmental Center
North Building
P.O. Box 41059 Minillas Station
Santurce, PR. 00904
(809) 727-8536

RHODE ISLAND
Peg Tormey, Executive Director
Rhode Island P&A System (RIPAS), Inc.
70 South Main Street
Providence, Rhode Island 02903
(401) 831-3150

SOUTH CAROLINA
Louise Ravenel, Executive Director
S.C. P&A System for the
Handicapped, Inc.
2360-A Two Notch Road
Columbia, S.C. 29204
(803) 254-1600

SOUTH DAKOTA
Robert J. Kean, Project Director
South Dakota Advocacy Project, Inc.
222 West Pleasant Drive
Pierre, South Dakota 57501
(605) 224-8294
(800) 742-8108

TENNESSEE
Sydney Ewell
Director of Advocacy
Tennessee State Planning Office
505 Deaderick Street
Suite 1800
James K. Pope Bldg.
Nashville, Tennessee 37219
(615) 741-2657

TEXAS
Dayle Bebee, Executive Director
Advocacy, Inc.
5555 N. Lamar Street, Suite K-109
Austin, Texas 78711
(512) 475-5543
(800) 252-9108

UTAH
Phyllis Geldzahler, Executive Director
Legal Center for the Handicapped
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(304) 346-0847
(800) 642-9205

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Madison, Wisconsin 53703
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(800) 362-9053

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508 Hynds Building
Cheyenne, Wyoming 82001
(307) 632-3496
(800) 442-2744

Appendix 6B

MENTAL AND DEVELOPMENTAL DISABILITIES FOR LEGAL ADVOCATES

Advocates for the Handicapped
2200 Merchandise Mart
Chicago, Il 60654
(312) 822-0435

American Association for the
Abolition of Involuntary
Mental Hospitalization
University of Santa Clara
Santa Clara, CA 95053
(408) 984-4361

American Civil Liberties Union
22 East 40th Street
New York, New York 10016
(212) 725-1222

American Coalition of Citizens
with Disabilities
1200 15th St., N.W.
Suite 201
Washington, D.C. 20005
(202) 785-4265

Architectural and Transportation
Barriers Compliance Board
Washington, D.C. 20201

Center for Public Representation, Inc.
520 University Avenue
Madison, WI 53703
(608) 251-4008

Center for Human Policy
216 Ostram Avenue
Syracuse, NY 13210
(315) 423-3851

Children's Defense Fund
1520 New Hampshire Ave. N.W.
Washington, D.C. 20036
(202) 483-1470

Children's Defense Fund of
Washington Research Project, Inc.
1746 Cambridge Street
Cambridge, MA 02138
(617) 492-4350

Disability Law Resource Center
at the Center for Independent
Living
2539 Telegraph Avenue
Berkeley, CA 94704
(415) 841-3790

Disability Rights Center
1346 Connecticut Avenue, N.W.
Washington, D.C. 20036
(202) 223-3304

Education Law Center, Inc.
605 Broad Street
Suite 800
Newark, NJ 07102
(201) 624-1815

Education Law Center, Inc.
2100 Lewis Tower Building
225 South 18th Street
Philadelphia, PA 19102
(215) 732-6655

Epilepsy Foundation of America
1828 L Street, N.W.
Washington, D.C. 20036
(202) 293-2930

Juvenile Rights Project of ACLU
Foundation
22 E. 40th Street
New York, NY 10016
(212) 725-1222

Legal Center for the Elderly
and Disabled
1722 J Street, Suite 19
Sacramento, CA 95814
(916) 446-4851

Mental Health Law Project
2021 L Street, N.W.
Suite 800
Washington, D.C. 20036
(202) 467-5730

National Association of the
Deaf/Legal Defense Fund
7th and Florida Ave., N.E.
Washington, D.C. 20002
(202) 651-5454

National Commission on
Confidentiality of Health
Records
1211 Connecticut Avenue, N.W.
Suite 504
Washington, D.C. 20036

National Juvenile Law Center
3701 Lindell Boulevard
St. Louis, MO 63108
(314) 533-8868

Western Law Center for the
Handicapped
849 South Broadway, Room 206
Los Angeles, CA 90014
(213) 972-0061

Youth Law Center
693 Mission Street
6th Floor
San Francisco, CA 94102
(415) 543-3307

ALLIANCES IN HEALTH AND EDUCATION:
Serving Youngsters With Special Needs

INSTRUCTOR'S GUIDE

Carolyn M. Del Polito

1983

The American Society of Allied Health Professions
One Dupont Circle, N.W., Suite 300
Washington, D.C. 20036

EC 161104

ALLIANCES IN HEALTH AND EDUCATION:
SERVING YOUNGSTERS WITH SPECIAL NEEDS

INSTRUCTOR'S GUIDE

by

Carolyn M. Del Polito, Ph.D.

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Cover photo: Marty LaVor © 1983.

This publication is based upon work performed pursuant to Grant No. 451 CH 00233 from the Office of Special Education and Rehabilitative Services, U.S. Department of Education. The points of view expressed herein are the authors and do not necessarily reflect the position or policy of the U.S. Department of Education.

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PREFACE

ALLIANCES IN HEALTH AND EDUCATION: SERVING YOUNGSTERS WITH SPECIAL NEEDS and this accompaning **Instructor's Guide** are outgrowths of the American Society of Allied Health Professions' (ASAHP) national advocacy initiative on behalf of children and youth with disabilities. ASAHP is pleased to provide these important publications for educators and practitioners in the related health and education professions who come in contact with youngsters with handicapping conditions. . .on the job, at home, or in the community. These educational tools can be used in the classroom, conference room, or clinic, particularly by those working in or preparing others to work in one of the following areas:

- Audiology/Speech Language Pathology
- Dental Hygiene/Assistance
- Dietetics/Nutrition
- Early Childhood Development
- Education Administration
- Medical Technology
- Nursing
- Occupational Therapy
- Pediatric Medicine
- Physical Therapy
- Physician Assistance
- Psychology
- Recreational Therapy
- Rehabilitation Counseling
- Social Work
- Special Education

The content included in **ALLIANCES IN HEALTH AND EDUCATION: SERVING YOUNGSTERS WITH SPECIAL NEEDS** addresses such critical issues as:

- Implications of Public Law 94-142 (The Education for All Handicapped Children Act) and Section 504 of the Rehabilitation Act for health professionals;

- Solutions to inefficiences, competition, and disparities in the delivery of services for youngsters with special needs and their families; and

- Attitudes and values of health and education professionals toward youngsters with disabilities and their families.

In addition, recommendations are included for improving collaborative efforts and communication among health and education professionals in identification, referral, and advocacy activities on behalf of youngsters and their families.

The text includes an in-depth discussion of six topic areas:

- **Legal Foundations**--addresses the rights, procedures, and services guaranteed by law and regulations for meeting the needs of children and youth with handicapping conditions.
- **Roles and Responsibilities**--identifies the barriers to effective service delivery and the health professional's roles and responsibilities in identifying, referring, and advocating for youngsters with disabilities.
- **Communication**--examines the barriers to effective communication with clients, parents, and colleagues and provides strategies for enhancing the professional's competence as a communicator.
- **Issues in Identification**--discusses the indicators of both high-risk and handicapping conditions in young children, emphasizing the professional's role in promoting non-discriminatory, multidisciplinary assessments of youngsters with handicapping conditions.
- **Referral, Coordination, and Management of Services**--identifies community, state, and national resources for the child or youth with a disability and provides strategies for accessing and coordinating these services.
- **Advocacy**--examines approaches to advocacy, identifies resources, and provides strategies for advocating on behalf of youngsters with disabilities and their families--from listening to their needs and concerns to supporting and promoting legislation on their behalf.

Each of these units addresses issues identified by an advisory committee of experts in allied health, education, and disabilities as critical to the knowledge base of practitioners in health and education--whether or not they interact directly or consistently with youngsters who have handicapping conditions. Further, these issues and the content included in the text have been field tested in seven regional sites across the country* with experienced service providers in health and education. Throughout the regions, the emphasis has been on **THE CHILD.** Similarly, **ALLIANCES IN HEALTH AND EDUCATION: SERVING YOUNGSTERS WITH SPECIAL NEEDS** and this **Instructor's Guide**, focus on the child, his or her needs, and the roles and responsibilities health professionals require to ensure appropriate services are coordinated for the youngster and his/her family. In addition, the instructional materials and strategies recommended in this **Guide** are based on the research literature in attitude change and instructional development and have undergone the same field testing as the content issues.

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* Regional sites have included California, Colorado, Maryland, Minnesota, Tennessee, Texas, and Vermont.

ASAHP extends its sincere gratitude to all the faculty members and resource persons who have assisted in both developing and testing these materials, with very special appreciation to Project Specialist Josephine Barresi and faculty members Ethan Ellis and Jayn Wittenmyer for identifying and or developing materials for this **Instructor's Guide**.

Hopefully, these tested materials will assist both health and education educators in integrating the content included in **ALLIANCES IN HEALTH AND EDUCATION: SERVING YOUNGSTERS WITH SPECIAL NEEDS** into their current curricular offerings. These materials similarly should assist educators and practitioners alike in designing workshops, symposia, conferences, and other continuing-education forums to address the issues related to the needs and rights of youngsters with disabilities and their families.

Reactions to these materials would be most appreciated. Please send your comments to: Dr. Carolyn M. Del Polito, American Society of Allied Health Professions, One Dupont Circle, N.W., Suite 300, Washington, D.C. 20036.

INTRODUCTION

The rights and needs of youngsters with disabilities and their families, as identified in **ALLIANCES IN HEALTH AND EDUCATION: SERVING YOUNGSTERS WITH SPECIAL NEEDS**, need to be addressed within health and education training programs--whether in core courses, specialized courses or seminars, or integrated throughout the curriculum. The issues are not new. The need for effective team approaches and coordination in both training and practice has been reiterated by health and education professionals throughout the country. For the most part, however, educators, whether in health or education, have received little or no training in coordinating ethical and humanistic care giving for youngsters with disabilities and their families.

To help alleviate the disparities and inefficiences in the delivery of services and to facilitate cost effective, quality care adapted to the unique, life-long needs of these youngsters, on-going professional development is as necessary for the educators as it is for the practitioners providing direct services. Those interested in developing programs, however, should beware of the "instant expert." The implications for the lives of students and the lives of their future clients demand that those designing and teaching the instructional programs possess the appropriate expertise, whether in health, special education, law, communication, or philosophy.

Further, there are two critical issues which must be addressed personally and professionally by those planning and presenting these instructional programs. These issues should be considered carefully, honestly, and as completely as possible.

- **Issue I: Recognizing and accepting one's own attitudes and values** towards persons with handicapping conditions, their families, and other providers in health and education serving these persons. In assessing one's own attitudes, the educator should review carefully the entire text, **ALLIANCES IN HEALTH AND EDUCATION: SERVING YOUNGSTERS WITH SPECIAL NEEDS.** Remember, educators--in any instructional context--communicate their own attitudes and values far more often than they communicate information about the topic of instruction. Furthermore, unless the educator's behaviors are consistent with the content communicated verbally, it is unlikely he/she will be perceived as a credible source of information; thus, having limited impact on students' knowledge or attitudes about serving youngsters with disabilities and their families.

  The **Introduction** of the text should be helpful, particularly in addressing individual attitudes and values as communicated by one's use of language--either in talking about or to persons with disabilities. One's language can indicate imbedded, often negative attitudes. It will be important for the instructional planner, therefore, to be cognizant of the impact of language and prepare other faculty (and students) with similar, appropriate understandings.

- **Issue II: Recognizing and accepting one's own technical competence** in each of the areas addressed in the text. Again, it will be necessary for the educator to be fully familiar with the content and related issues presented in the text. Along with reviewing the text and the suggested readings, educators should feel free and are encouraged to solicit guidance from colleagues who are experts in each of the respective areas (i.e., legislation, communication, disabilities, education, advocacy, etc.) to provide resources and/or assistance in instruction.

To assist the reader and his/her students in achieving desired competencies, a statement of purpose and a list of learning objectives opens each unit of the text. In addition, lists of national, state, and local organizations, agencies, and other resources, including annotated lists of suggested readings are included. The additional readings were selected to supplement the material in each unit, providing either a more detailed treatment of some aspect of the subject or a referenced guide, suitable for sharing with clients and their families. Instructors may wish to preview these readings in preparation for their training programs and arrange for some to be available as references for learners.

This **Instructor's Guide** provides both general **Planning and Operating Strategies** for training programs and specific **Content-Related Instructional Strategies** for each unit contained in the text. The planning and operating strategies include general design recommendations for conducting any instructional program, including:

- Methods for determing the goals of the instructional unit;
- Recommendations for designing the overall operational plan, including participant selection and application procedures, evaluations, and budget proposals; and
- Considerations for designing instructional strategies, including content, structure, and procedural suggestions.

In addition, a sample workshop agenda is shared with specific content and learning strategies identified.

The content-related strategies, on the other hand, are specified for each unit in the text and include:

- Discussion questions to probe the learner's experience, knowledge, and attitudes;

- Suggestions for realistic, out-of-classroom learning experiences to help the learner expand his/her expertise;
- Strategies for tapping community resource persons for their assistance and expertise;
- Media suggestions to add variety and interest; and
- Masters for overhead transparencies and handouts to use as teaching tools.

Both the general planning strategies and the specific content-related instructional strategies are provided in outline form for clarity and quick reference.

SECTION ONE

PLANNING AND OPERATING STRATEGIES

The following suggestions for planning instructional units can be adapted for an hour seminar, a one-to-three day workshop, a two-to-four week unit within another course, a semester course, or a complete program of several courses for providers of health and education services.

I. Needs Assessment:

Generally, an instructional unit is designed in response to the needs and concerns felt by constituents--whether they be students, faculty, administrators, or practitioners. Thus, prior to the development of any instructional unit, constituents' needs and concerns must be known. If not previously identified, several options for assessing needs are available to the planner.

A. **Invite constituent respresentatives to participate on a planning committee.** Panel members should include representatives (opinion leaders) of constituent groups: individuals who likely would know and understand their constituents' concerns as well as possess the ability and willingness to engage in problem-solving discussions with others to resolve the identified dilemmas/concerns of constituents.

Based on ASAHP's experience, an appropriate and helpful advisory council or planning committee would consist of representatives from allied health, regular education, special education, medicine, communication, parent groups, consumers with disabilities, and the institutional/organizational and/or state agencies in health and education.

These representatives will be able not only to provide expert advice regarding their constituents and the issues, but also insightful recommendations for learning objectives, procedures, and resources--human and material. In addition, as credible leaders within their professional spheres, the opinions of these representatives undoubtedly will be sought out and listened to by their constituents. Their understanding of and agreement and commitment to the program's instructional objectives and design, therefore, will be crucial for the success of a training program--particularly with their constituents. Their involvement and approval will legitimize the training effort and assist in the promotion of the program.

B. **Conduct a survey to assess the needs of potential audience members.** A second option for assessing needs is to design a questionnaire which would assess the students'/professionals' knowledge and perceptions of their roles and responsibilities toward youngsters with handicapping conditions.

Questionnaire development may include a question brainstorming session with resource persons; a critique of initial questions by other experts in health and education; and a field test of the entire survey and cover letter for clarity, completeness, accuracy, and relevance by other resource persons not participating in the questionnaire development.

A questionnaire can serve several purposes. Primarily, the responses provide relevant information about the perceptions, knowledge, skills, and attitudes of the professionals surveyed. Findings can be used in the design of both content and instructional strategies for the program.

In addition, however, a questionnaire can provide some additional benefits whether or not it is returned. Depending on the questions asked, a survey may:

- Raise the respondents' awareness of the need to be concerned about their roles and responsibilities for youngsters with handicapping conditions;
- Stimulate the respondents to seek out more information about Public Law 94-142 and their roles and responsibilities for youngsters with handicapping conditions; and
- Educate the respondents to some extent about appropriate advocacy behaviors.

A sample needs assessment questionaire is included in Appendix A.

II. Purpose or Goal of Instructional Unit:

Once the needs, concerns, and demographics of the audience have been identified, the purpose or goal of the instructional unit can be determined. The overall and specific objectives of the unit should be clear to all those involved in the unit's design and implementation. For example, the general goal of a one-day seminar conducted in Texas for leaders in the health professions was:

> To disseminate information and sensitize related health professionals in Texas to recognize and accept their expanded roles and responsibilities for meeting the needs and rights of youngsters with disabilities and their families.

III. Operational Plan for Instructional Unit:

There are a number of questions to be considered by the planners for this or any other instructional unit once the overall purpose is determined. Preferably, these questions would be considered by the representatives from the various audience constituencies identified above for an advisory council or planning committee.

A. Questions for Considerations in Planning Technical/Logistical Aspects of the Program:

1. Who should be invited to attend?

- Educators?
- Health Practitioners?
- State Association Leaders?
- Chief Administrators?
- Program Directors?
- All Groups?

Because a major issue in effective provision of services is the need for communication and collaboration, all persons involved in meeting the needs of youngsters with handicapping conditions--including those involved in personnel preparation and delivery of services--should be considered as potential audience members.

2. Which professions should be included?

- Audiology/Speech Language Pathology
- Dental Hygiene/Assistance
- Dietetics/Nutrition
- Medical Technology
- Rehabilitation Counseling
- Special Education
- Early Childhood Development
- Pediatric Medicine
- Nursing (Public Health/School)
- Social Work
- Occupational Therapy
- Physical Therapy
- Physician Assistance
- Psychology
- Recreational Therapy
- Vocational Education
- Education Administration
- Others?

When possible, a variety of professional groups in related health, education, and medicine should participate together. Instructional units can be designed to enable the providers to:

- learn about each others' professional roles and skills;
- establish new support networks which hopefully will be transfered to their own work situations; and
- learn to work cooperatively with a variety of professionals concerned with one goal: providing appropriate services for youngsters with handicapping conditions.

The design of the socialization process used in ASAHP's training activities to involve a variety of professionals has been extremely important to achieving the instructional goals and to the overall effectiveness of individual programs. Numbers of participants, therefore, have been limited to a maximum of 50 persons. With changes in group size, the instructional design and learning strategies will need to be modified accordingly.

3. Are there other persons who should be involved either as participants or resource persons?

- Parents of youngsters with disabilities
- Consumers/adults with disabilities
- Professional advocates
- Lawyers
- State or local health or education agency administrators

The expertise these persons can bring to a training event for service providers in health and education cannot be over-estimated. Truly, among the most critical concerns for any planning group should be ways of involving both consumers and parents in planning and presenting the training activities.

Recommendations for local faculty, speakers, and resource persons should be sought from your advisory council. In addition, **Units 5 and 6** of the text list numerous agencies which can be contacted for local experts. Particularly good contacts will be your state's Protection and Advocacy (P&A) System, Independent Living Centers, Developmental Disabilities (DD) Council, and Special Education Department. Educational administrators and teachers, along with parent and consumer advocates, provide a well-rounded perspective on the issues faced in providing efficient, cost-effective services to youngsters with special needs. Additional suggestions are provided in the next section on content-related strategies.

4. What process should be used to solicit participation in the training program?

A planner's promotional options are many, including news releases to local media, personal invitations, and brochures and/or letters mailed directly to potential participants. For many of ASAHP's training programs, a nomination and/or an application procedure preceded acceptance of participants in the program. The nomination procedure emphasized the "specialness" of the training activity and the uniqueness of all participants. The application process provided potential participants with an opportunity to express their involvement and interest in working with children and youth with disabilities, indicating their openness to new roles related to Public Law 94-142. Similarly, in asking about their advocacy potential or advocacy interest, individuals were identified who had more favorable attitudes toward change, and thus would likely be willing to promote advocacy initiatives for youngsters with handicapping conditions and become articulate role models for colleagues in health and education.

These procedures may prove to be too time-consuming for many instructional planners; however, if possible, commitment to the goals of instruction prior to participation will increase the likelihood of success and the overall satisfaction of participants.

5. Are additional materials needed? Where can they be obtained?

A number of additional readings and resource materials are identified at the conclusion of each unit in the text as well as in the next section on content-related strategies. Local agencies, as identified in **Unit 5** of the text, also can provide resource materials on both the issues and available local services for meeting youngsters' health and education needs.

6. How will the training event be evaluated? How will the need for follow-up activities be determined?

The program planners' concern, of course, is with the full and efficient implementation of the program's goals. Energies will be devoted to designing quality learning experiences for all participants, selecting faculty and other presenters who are energizing speakers and leaders within their respective professions, and carefully assessing the impact the program has on both the individuals involved and the youngsters they serve.

As discussed previously, the pre-assessment questionnaire can be designed and used to ensure program procedures (content and presentational strategies) focus on the appropriate concerns of the professionals. In addition, assessing the participants understanding of the issues prior to the program provides base-line data for follow-up evaluation of changes in the professionals' (a) knowledge and attitudes; (b) perceptions of their roles and responsibilities for children and youth with handicapping conditions, as well as (c) behaviors implemented as a result of their new knowledge and involvement in the training program. The results also will help to identify areas where additional, specialized training will be required.

In addition, descriptive, evaluative information regarding the program's effectiveness can be provided through daily and final feedback forms which can solicit the participants' reactions to both (a) the content and organization of the training event, and (b) the instructor/speaker's style and quality of presentation. Space also can be provided on the forms for the participant to indicate the program's special benefits and any additional information or training they desire. This information will be helpful not only for the faculty and speakers in adapting and polishing future presentations, but also for making modifications for the overall design and content of future training programs. Sample evaluation forms are provided in Appendix A.

7. **Budget and Time Considerations:**

- Equipment Rentals
- Resource Materials: Books, Manuals, Films, etc.
- Materials Development
  - Surveys/Questionnaires
  - Applications
  - Training Materials
  - Registration Packets
    - Agendas
    - Faculty/Resource Person Biographies
    - Participant Lists
    - Badges
    - State and/or National Resource Lists
- Promotional Materials
  - Press Releases
  - Brochures
  - Letters
- Production/Duplication
- Postage
- Accomodations
  - Meeting Room
  - Sleeping Rooms
- Food Functions
  - Breakfast(s)
  - Beverage break(s)
  - Luncheon(s)
  - Reception(s)

As costs are determined for materials development, space, equipment, and other activities associated with the training program, planners will need to evaluate available fiscal resources, and determine whether outside funding sources should be explored, or whether a registration or similar fee structure will be required to cover costs. As noted previously, food functions are important socializing and networking times and may help to fulfill a number of the program's objectives. When agency or institutional budgets do not provide sufficient resources for food functions, a modest participant registration fee should be considered. A sample budget outline as well as a check-list for program development is provided in Appendix B.

B. Questions for Consideration in Designing Instructional Strategies:

1. **What are the specific goals or desired outcomes of this training event?** Planners may consider using the following format: Upon completion of this training event, participants should:

• Understand . . .	(Knowledge Level Objectives)
• Be sensitive to . . .	(Affective Level Objectives)
• Be able to . . .	(Performance or Behavioral Level Objectives)

The learning objectives which lead each unit of the text emphasize the critical training components for health and education professionals serving youngsters with special needs. Planners should consider these objectives as well.

2. **What issues should the content emphasize?** In addition to the specific goals of the program, planners should consider:

   - Needs and concerns of participants
   - Knowledge level and experience of participants
   - Expectations of participants

A needs analysis should clarify gaps in knowledge and issues of concern for participants. The text, as well as members of your Advisory Council, similarly can help in focusing the content of the instructional unit.

3. **To what extent should the instructional program be structured?**

   - Instructional Strategies
     - Lecture-Forum
     - Discussion
     - Small-Group Working Sessions
     - Media Presentation/Discussion
     - Case-Study/Discussion
     - Simulation/Role Playing

   - Social/Networking Considerations
     - Group Assignments
     - Food Functions

Whatever decisions the planners make with respect to the types of instructional approaches to be used in the training program, the entire program should be planned carefully and methodically, taking into consideration all information known about the prospective participants. Thus, recognizing that the audience members' fundamental attitudes about their roles and responsibilities for youngsters with handicapping conditions will not be changed easily, planners and faculty should design the instructional materials and the method of presentation to create situations in which participants will be inclined to accept their new roles and responsibilities.

Rogers with Shoemaker (1971) conceptualize four main steps in the innovation-decision (change) process: (1) the **knowledge function** which occurs when the individual is exposed to an innovation or new concept and gains some understanding of it; (2) the **persuasion function** which occurs when the individual forms either favorable or unfavorable attitudes toward the innovation; (3) the **decision function** when the individual decides to adopt or reject the innovation; and (4) the **confirmation function** which occurs when the individual solicits reinforcement for the decision (the individual may reverse a previous decision if exposed to conflicting messages about the innovation).

In ASAHP's training activities, faculty were careful to move toward the receivers psychologically rather than move against them. In an opening address, for example, a presenter can build rapport with the audience by presenting shared premises. In addition, the opening can orient the audience to the entire instructional program by (1) providing an overview of the program; (2) emphasizing the importance of the participants' involvement in the program; (3) clarifying the goals and the plan of the instructional unit; and (4) specifying the planners' expectations for the participant's participation.

This approach is reinforced in several studies (Papageorgis, 1968; McGuire, 1969). In fact, as Mills (1966) has shown, disclosure of intent is especially effective if the presenters couple it with expressed liking for the audience members. The explicit approach has been found to be more effective in helping to shape attitudes (Irwin and Brockhaus, 1963; Weiss and Steinback, 1965) and has been used in the workshops and conferences designed for ASAHP's Advocacy initiative.

Further, the overall organizational pattern of the unit should be planned. An approach used and recommended for creating desired responses reflects Monroe and Ehninger's (1964) "motivated sequence" of organization which includes:

- Gaining the audience's attention;
- Clarifying the causes of the problem and establishing the need for change;
- Providing the recommended action for change with approaches to implement the change;
- Helping the audience visualize what the implications of both non-action and action would be; and
- A final call for implementing the recommended activities.

Because this approach follows a systematic thought process for solving problems, it is more likely to motivate the listeners to accept recommended practices in identification, referral, and advocacy.

Specific instructional strategies are provided for each of the units in the next section. Depending on the experiences of audience members, faculty expertise, and available resources, however, numerous other approaches may be used as well. The strategies recommended are only suggestions, provided to assist in initial planning sessions.

It will be important, however, to promote social interaction among participants during both instructional and free-time activities. Unquestionably, informal personal relationships and contacts are significant predecessors for building alliances and networks across the professions, enhancing communication, and improving access to services for youngsters and their families. Opportunities for interaction via small group discussions, action agenda development, luncheon and dinner meetings, as well as socializing informally for beverage breaks or cocktails, are critical in any instructional plan designed to build cooperative relationships.

4. **How much time is required to achieve seminar/program goals and meet participants' expectations?** The time elements will be determined necessarily by the:

   - Amount of content to be covered
   - Instructional strategies selected
   - Amount of time available
   - Expectations and experiences of participants
   - Other time demands/limitations of the institution/agency

Again, an advisory/planning committee can assist in determining activity and over-all program timing.

5. **What expertise should Faculty and or Resourse Persons possess to achieve desired results?**

Recommendations for resource persons and specific areas of expertise are identified in the next section on **content-related strategies.** Along with being an expert within his or her own field, however, each of the faculty members should be experienced in adapting to the needs of audience members. Presentations should possess vivid, metaphorical language, interesting supporting materials, including appropriate statistics, analogies, and humor, and a clear organizational style.

A training session with faculty members and resource persons is strongly recommended. Along with polishing skills, it also affords an in-depth review and evaluation of the content and presentational strategies planned for the instructional units.

The following further describes ASAHP's program development activities for two-day regional workshops. Similar strategies were used for other advocacy-initiative conferences and seminars.

IV. Program Development: ASAHP's Plan

In a two-and-a-half day meeting of the Advisory Council for ASAHP's Regional Workshops, cognitive and affective competencies for the participants were identified. ASAHP staff then designed the workshop content and instructional strategies in response to the concerns and issues raised by the Advisory Council. Specifically, workshop content and instructional strategies were designed to:

1. Identify the emerging roles and responsibilities of health professionals related to Public Law 94-142;

2. Identify the competencies required of these professionals to meet their roles and responsibilities in identifying, referring, and advocating for children and youth with handicapping conditions;

3. Identify specific strategies health professionals can utilize to implement their new roles and responsibilities; and

4. Provide opportunities for health professionals to implement and practice their newly acquired competencies.

The workshops' content and design were further reviewed and analyzed by resource persons in the Washington, D.C. area with final modifications made by the workshop faculty. During the planning sessions, faculty and staff reviewed and revised the agenda, and identified audio-visual, print, and human resources based on the survey analyses and the participants' application. In addition, faculty contributed detailed outlines and articles which were compiled into a Resource Manaual and distributed to participants.

The workshops were planned for two days, opening on Thursday afternoons and ending on Saturday afternoons as recommended by the Advisory Council. A variety of instructional strategies were employed: panel presentations, lectures, and video-tapes and case studies combined with small group discussions.

A. Faculty/Speaker Selection: The faculty selected to participate in the training workshops were among thirty-three individuals nominated by the Advisory Council, resource persons, and staff. Three of the faculty have been asked to write chapters in the text accompanying this **Guide**: Anthony Bashir, Ethan Ellis, and Jayn Wittenmyer. For each of the workshops conducted across the country, local resource persons were invited to participate, including individuals representing state departments of special education, regular education, consumers with handicapping conditions, health professionals, parents of children with handicapping conditions, and advocacy agencies. Brief biographies for each of the faculty members, staff, and resource persons were included in registration packets along with the agenda. The expertise exhibited by each of these individuals has been outstanding; each has added much to the overall effectiveness of the workshops.

B. Program Modifications: Modifications in the design of the workshop and the training strategies were made continuously throughout the two and one-half years of workshop development and training. Changes were based on (1) survey data, (2) the changing federal and state scenes, (3) the feedback received from faculty, staff, and resource persons, and (4) the caliber of individuals applying for the workshops. Each revision responded to the needs of our participants while fulfilling the goals of the program. The final revisions reflected more small-group working sessions in which participants had an opportunity to share their expertise, with faculty members assuming a more facilitative rather than instructive role. Because the faculty worked well as a team and possessed such high levels of expertise in their professional areas, they were able to respond with ease to participants' concerns, allowing much more flexibility with group discussion formats than initially planned.

C. Resource Materials: Each of the workshop participants received a 350-page Resource Manual with detailed outlines and resource information for professionals interacting with children and youth with disabilities and their families. The text, **ALLIANCES IN HEALTH AND EDUCATION: SERVING YOUNGSTERS WITH SPECIAL NEEDS**, addresses and updates the issues contained in the Resource Manual. Limited copies of the manual with additional articles and reference materials can be obtained from the American Society of Allied Health Professions for the cost of reproduction and mailing, approximately $40.00.

D. **Workshop Agenda and Strategies:** The following outlines a two-day workshop agenda with a discussion of the rationale for the organization of content and use of instructional strategies. A sample Agenda with designated speakers is provided in Appendix B. Additional materials for each unit in the text are provided in the next section on **content-related strategies.** All of these materials are provided to assist planners in designing instructional programs appropriate for their constituents.

WORKSHOP AGENDA

STUDY SESSION ON PUBLIC LAW 94-142

THURSDAY

9:30 am	PRE-WORKSHOP REGISTRATION
10:00 am	STUDY SESSION ON PUBLIC LAW 94-142
11:30 am	ADJOURNMENT

Purpose: To prepare participants for the workshop by providing them an opportunity to review the Education for All Handicapped Children Act (Public Law 94-142).

Objectives:

1. To clarify the legislation and current regulations regarding Public Law 94-142;
2. To discuss the relationship of Public Law 94-142 to Section 504 of the Rehabilitation Act; and
3. To discuss the implications of the legislation for health professionals.

Presentation Strategy/Discussion: This was designed as an optional session, recognizing the range of experiences participants will have had with PL 94-142, Section 504, and their regulations. Faculty members and/or local resource persons have presented this one-and-a-half hour session using a lecture/discussion format. A brief pre-workshop questionnaire provided the presenters with the unique concerns/questions of the participants prior to the session.

12:00 pm WORKSHOP REGISTRATION; PICTURE PROFILE OF PARTICIPANTS

During registration, faculty and/or resource persons met the participants and asked them to pose for a polaroid picture. Pictures of all attending affixed with names and affiliations, were attached to flip chart paper and hung on the wall during the entire training program. This procedure is a good "ice-breaker," providing all participants and faculty with an opportunity to connect names with faces. It assists greatly in network-building and creating cohesion among all participating.

1:00 pm OPENING ADDRESS: "Meeting the Challenge Through Alliances"

Purpose: To prepare participants for the program both intellectually and psychologically.

Objectives:

1. To present the problem/reason for the program;
2. To provide background information on the program's development, the goals of the program, and the planners' expectations for the program's outcome;
3. To stimulate participants to want to become involved with the issues and address them; and
4. To introduce participants to faculty, resource persons, and guests.

Presentation Strategy/Discussion: As noted in the earlier section, the opening is quite important in involving participants in the program's goals and outcomes. This session was presented in lecture format by the program director, generally following a brief (5-10 minute) welcome by a host or local dignitary. The strategies employed in this opening session have been discussed previously in the section on the structure of the instructional program.

1:45 pm PERSPECTIVES ON THE LAW: Rights of Children and Youth With Handicapping Conditions

Panel with Moderator:

"The Current Political Climate"
"The Parent's Response"
"The Consumer/Client's Response"
"The Health Provider's Response"
"The Audience Response"--Questions and Discussion

Purpose: To discuss the current political climate and the implications of PL 94-142 and Section 504 for children and youth with handicapping conditions from the unique perspectives of the panel members. The perspectives represented included those of parents, consumers, health providers, and educators.

Objectives:

1. To discuss the implications of federal legislation for the rights of children and youth with handicapping conditions, including their rights to:
    a. A free and appropriate public education;
    b. Access to services, programs, and facilities;
    c. Due process;
    d. Equal opportunity based on capability;
    e. A least restrictive educational environment;
    f. Individualized Education Programs (IEP); and
    g. Special education and related services.
2. To discuss the differences between federal and state legislation regarding the rights of youngsters with disabilities and their families.
3. To promote sensitivity to the educational and health-related service needs of these youngsters.

Presentation Strategy/Discussion: A faculty member generally presented information regarding the current, national political climate regarding the legislation. Panel members then presented their perspectives. Views were heard from:

- Special Educators (IEP; Free and Appropriate Education)
- Regular Educators/Educational Administrators (Access/Equal Opportunity/Costs)
- Parents (Due Process; Consent to Evaluation and Changes in Placement, Pre-School Concerns)
- Consumers (Least Restrictive Educational Environment and Section 504 Procedures)
- Health Professionals (Related Services)

The presentations were followed by a question and answer period.

3:15 pm BREAK

3:30 pm PERSPECTIVES ON GROWING UP DISABLED: Implications for the Service Provider

With a Response From:

- Consumers/Clients
- Parents
- Educators
- Service Providers

Purpose: To sensitize participants to the needs and concerns of youngsters with handicaps as they grow into adulthood.

Objectives:

1. To discuss the myths and the realistic perceptions of persons with disabilities regarding:

    - interactions with family members
    - interactions with health and education professionals
    - preparation for adulthood
    - social/physical accessibility
    - employment opportunities

Presentation Strategy/Discussion: A faculty member or resource person, utilizing a lecture-forum (question and answer) format, presents an overview of the myths and stereotypes faced by persons with disabilities. Provocative video tapes showing adults with disabilities talking about their experiences relative to these stereotypes then are presented, followed by an open, full-audience discussion of the issues, including responses from resource persons and faculty.

STRATEGIES FOR INITIAL SESSIONS

These initial sessions were designed to create dissonance in the minds of the audience by providing evidence of how the rights and needs of children and youth with disabilities are not being met currently. The stimulus materials (the panel presentation which included a special educator, a regular educator, a parent of a child with handicapping conditions, a consumer with disabilities, and a health professional, as well as emotionally provocative video-tape presentations) were designed to stimulate a psychological imbalance (i.e., dissonance, incongruity, etc.). Since psychological imbalance is unpleasant and uncomfortable (Hider, 1958; Festinger, 1957; Brehm and Cohen, 1962; Osgood and Tannenbaum, 1955), the participants generally were ready to discuss the issues from their perspectives as health professionals in efforts to reduce any perceived incongruity with their current perceptions.

Changes in attitudes are only one means of relieving dissonance; however, the program was designed to help the participants "rebalance" their cognitions by providing them with specific strategies to help children and youth with handicapping conditions receive appropriate services. The strategies identified during the training program, (jointly by participants and planners), therefore, must be perceived by the participants to have elements which are: consonant with their cognitions, satisfy their values, have social support from other persons whom they hold in high esteem, and meet objections which they or others might raise (Simons, 1976, p. 127). Based on individual-session and overall-program evaluations, these goals were met.

4:15 pm PARTICIPANT INTRODUCTIONS (Small Groups Categorized Across Professions)

Purpose: To provide time for participants to meet and get acquainted with the other members of their small groups.

Objectives:

1. To identify other members of the small group by name and home community;
2. To identify the professional roles and expertise each member represents;
3. To recognize the extent to which their small group members interact with children and youth with handicapping conditions;
4. To acknowledge the diversity of the backgrounds and expertise represented in their groups and, therefore, in the workshop generally; and
5. To identify group members' expectations of the workshop and major concerns which need resolving.

Presentation Strategy/Discussion: A cross-section of the health professionals attending, generally from the same state, are asked to participate in a small-group exercise (8-12 persons) in which each person interviews the person sitting next to them, solicits information on the above objectives, and then introduces their partner to the entire group. Faculty and resource persons facilitate the exercise.

5:00 pm INTRODUCTIONS TO ENTIRE AUDIENCE

Purpose: To provide time for participants to learn at least one bit of information about each participant in the room.

Objectives:

1. To identify the area of expertise each participant brings to the session; and
2. To identify each participant's major concerns or linkages to other networks which they wish to share.

Presentation Strategy/Discussion: Since this general-audience introduction is followed by an informal reception (cocktails; wine and cheese; etc.), participants are asked to introduce themselves to the entire audience, providing or soliciting one unique piece of data regarding:

- interest/concerns;
- special programs;
- networks/alliances; and/or
- resources (human and material).

Using this approach, audience members are able to identify others within the audience, in addition to their small-group members, whom they might wish to talk with during the reception or later in the workshop. Throughout the training program, participants are encouraged to learn about one another--both professionally and personally--to benefit maximally from the sessions and to expand their existing networks of resources.

6:30 pm RECEPTION

As noted previously, social interaction and networking among participants has been a primary goal of the program to:

- Enhance participants' understanding of one another's professional roles and responsibilities;
- Ease communication barriers; and
- Develop and expand resource networks.

Generally, a reception was sponsored by a local host institution or jointly by several state professional associations.

FRIDAY

8:00 a.m. CONTINENTAL BREAKFAST AND BREAKFAST MOVIE

Each morning of the workshop a continental breakfast was served, during which time a movie and/or video-tapes were shown. Since there are generally numerous resource materials to share with participants and limited time in which to share them, ASAHP planners decided to combine breakfast with a movie/video-tape. Materials shown were selected by the faculty with care, ensuring all materials reflected a non-biased, non-stereotypical philosophy while meeting the goals of the activities which would follow. Suggestions for non-print media resources for each unit are contained in the next section on **content-related strategies.**

8:45 am BARRIERS TO THE DELIVERY OF SERVICES

Purpose: To identify the barriers to effective service delivery for professionals serving youngsters with disabilities and their families.

Objectives:

1. To identify and discuss specific barriers/constraints within and across the health and education professions of those participating which impede efficient, cost-effective services to youngsters with disabilities and their families.

2. To compare the barriers identified during the workshop with those identified by others in health and education.

Presentation Strategy/Discussion: Participants, categorized across professions, meet in small groups (8-12 persons) to discuss the barriers to effective and efficient service delivery and record their deliberations on flip-chart paper. Faculty members and resource persons facilitate the discussions. Small groups are directed to:

- Identify barriers;
- Classify the barriers according to the importance of resolving the issue/barrier;
- Cluster/categorize barriers, as appropriate (e.g., knowledge issues--identification, referral, communication, and advocacy issues; or attitudinal, procedural, regulatory, informational and funding issues);
- Prioritize issues (i.e., need for early resolution); and
- Report to the entire group.

Note: Facilitators of the small groups should be familiar with the content of **Unit 2** in the text to assist group processing.

10:15 am BREAK

10:30 am IMPLICATIONS FOR SERVICE PROVIDERS

Purpose: To identify the roles and responsibilities of health professionals in identifying, referring, and advocating on behalf of children and youth with disabilities.

Objective:

1. Having listened to the previous presentations and videotapes on the needs and rights of youngsters with handicapping conditions, participants will discuss and identify the roles and responsibilities health professionals should be prepared for in relating to youngsters with disabilities and their families.

Presentation Strategy/Discussion: Participants, categorized across professions, meet as small groups (8-12 persons) to discuss their roles and responsibilities and record their deliberations on flip-chart paper. A faculty member or resource person facilitates the discussion. Small groups are directed to:

1. Select a group member to record the group's deliberations on a flip chart provided;
2. Cluster/categorize the roles and responsibilities; and
3. Select a group member (may be the recorder) to present the groups's final list of roles and responsibilities of health professionals to the entire conference group.

Note: Facilitators of the small groups should be familiar with the content of **Unit 2** in the text to assist group processing.

STRATEGIES FOR SMALL GROUP SESSIONS

These two small group sessions have been critical components for the overall success of the workshops conducted by ASAHP. Utilizing what Bettinghaus (1973) calls participatory persuasion, the small group sessions provided participants with an opportunity to identify (with the guidance of a faculty facilitator) barriers to services and their roles and responsibilities--in writing (on newsprint) to be shared with the entire audience. Havelock (1971) suggests "the two critical factors for participants' commitment to their new roles will be (a) the perceived consensus among their peers; and (b) the fact that they had made a decision regarding it" (p. 5-2).

Because participants will bring extensive expertise to the workshop, the group's efforts will uncover most, if not all, of the points which are expanded on during the rest of the workshop. By having participants announce their perceived roles, they will be more ready to become committed to those roles, to further their understanding of implementing those roles, and therefore, become more committed to the content and activities designed for the rest of the instructional program. This approach mirrors Simons (1976) recommendation in which he suggests, "if at all possible, the preliminary commitment should be of a public nature and should entail some effort on the part of the individual" (p. 244).

Additionally, if the participants come from a variety of health professions, little cohesion will be observed initially. To develop close interpersonal rapport and member cohesion within the training program, the first afternoon's activities should be designed to stimulate group interaction. "As we know group pressures to modify beliefs or behavior will be more strongly felt by those attached to the group" (Rogers with Shoemaker, 1971, p. 290).

With most instructional programs of this type, as with ASAHP's workshops, it will be the first time participants will be involved in an instructional setting with other professionals from diverse professions--particularly to discuss their roles and responsibilities for youngsters with handicapping conditions. Because of this diversity, faculty and resource persons must be prepared for the unexpected and to modify group and/or lecture presentations. Further, they will need to stress activities/behaviors the participants can pursue in reference to the program's goals; e.g., in identification, referral, and advocacy procedures for children and youth with disabilities. For, as Simons (1976) warns, "new attitudinal commitments may be sufficiently satisying in themselves so that action becomes psychologically unnecessary" (p. 90). While for ASAHP's programs, commitment to specific, future advocacy initiatives was desired, for all instructional programs, behavioral or attitudinal change is desired to indicate learning has occured. Thus, these suggestions should be helpful in designing any instructional program.

12:00 pm LUNCHEON WITH GUEST SPEAKER

A sit-down luncheon was prepared for participants to continue networking. In addition, in most cases a guest speaker was invited to present a 20-25 minute talk on a topic relevant to the goals of the program. Such topics included:

"Nonverbal Communication in the Provision of Health-Care Services"

"The Roles of Health Professionals and Persons with Disabilities: A Shared Dilemma"

"Genetics: Implications for the Health-Care Provider"

Participants do need a "break" from the intensity of the workshop program. Guest speakers, when scheduled, therefore, are asked to maintain the requested time limits for their presentations, allowing at least a half-hour of free-time.

2:00 pm FORECAST FOR THE FUTURE: ALLIANCES IN ADVOCACY

Purpose: To review and summarize the previous sessions' conclusions and to refocus the group's attention on the anticipated outcomes of the workshop.

Objectives:

1. To summarize briefly the outcomes of the small group sessions on "barriers" and "roles and responsibilities."
2. To review the previous sessions' conclusions in relationship to the program's goals and the power/ability of health professionals to solve these problems.
3. To identify the critical issues in affecting change on behalf of youngsters with disabilities and their families, including:
    - Knowledge of rights and needs of youngsters with disabilities
        - Laws and regulations (Local/State/Federal)
        - Disabling conditions and the implications of these conditions for a free appropriate public education
        - Issues in diagnosis: educational planning and treatments

- Communication skills and strategies
- Referral sources and strategies
- Advocacy models and strategies

Presentation/Strategy: Lecture-forum by program director.

2:20 pm	ADVOCACY MODELS
3:00 pm	BREAK
3:15 pm	REFERRAL SOURCES AND STRATEGIES
4:00 pm	COMMUNICATION SKILLS AND STRATEGIES

Purpose: To respond to participants' concerns regarding:

- Approaches to advocacy for youngsters with disabling conditions and their families;
- Referral sources and strategies for obtaining appropriate referrals for clients and their families; and
- Communication barriers to effective service delivery and the skills and strategies providers need to help alleviate those barriers.

Objectives: In general, the objectives for these three sessions reflected those included in the accompanying text for:

- **Unit 3**: Communication;
- **Unit 5**: Referral, Coordination, and Management of Services; and
- **Unit 6**: Advocacy (Objectives 1, 2, and 3)

Presentation Strategy/Discussion: Since many of the issues related to advocacy, referral, and communication would have been raised previously in the small group sessions and reports on "barriers" and "roles and responsibilities," the faculty planned a flexible approach for these sessions.

Prior to the luncheon, each of the small groups were asked to identify three key questions in each of the above areas which required further elaboration and/or discussion. During lunch, the questions were reviewed and organized, and presented to the faculty for response. Generally, the sessions became discussions with the entire audience, facilitated by the faculty members. The faculty were careful to cover the major critical issues in their particular section, whether or not a question was posed. Again, the accompanying units in the text identify the objectives and content to be addressed. Although the time available precluded in-depth discussions of the issues during the actual workshop presentations, informal sessions during free times were held consistently by faculty and resource persons. Appendix B contains sample questions asked of faculty.

5:30 pm ADJOURNMENT

SATURDAY

8:00 am CONTINENTAL BREAKFAST AND BREAKFAST MOVIE

(See Friday 8:00 am schedule for details.)

8:45 am ADVOCACY: COMMITMENT AND IMPLEMENTATION

I. "Strategies for Effective Advocacy"

Purpose: To clarify the advocacy needs of children and youth with handicapping conditions and the diverse roles health professionals may assume in the advocacy process.

Objectives:

1. Discuss the concept of "advocacy" as a role for health professionals.
2. Identify existing or potential coalitions and independent groups with whom to effectively advocate on behalf of children and youth with disabilities.
3. Identify and utilize resources for effective advocacy appropriately.
4. Identify barriers to and solutions for effective advocacy.

Presentation Strategy: Lecture-Forum

9:45 am BREAK

10:00 am ADVOCACY: COMMITMENT AND IMPLEMENTATION (continued)

II. "Implementing Effective Advocacy Strategies"

Purpose: To promote participants' development of effective advocacy strategies for their own employment and community situations.

Objectives:

1. To identify the current conditions of personal work and community environments and recommend specific strategies for effective advocacy.

2. Identify possible strategies for dealing with pitfalls to effective advocacy, such as:

   - conflict of interest;
   - resistance to change; and
   - discriminating policies and practices.

3. Develop strategies for expanding advocacy efforts in their own health facilities, communities and/or in their local, state, or national professional societies.

Presentation Strategy/Discussion: To achieve further commitment and follow-through on the program's goals, this last session of the workshop again uses a group-discussion approach. Prior to the session, the particpants will have been asked to identify the problems they perceive in their home situations which interfere with children and youth's access to appropriate services. During this final session, using structured guidelines and with the assistance of other small group members, they develop their own personal and professional advocacy initiatives to respond to those problems, writing their goals on carbonless paper. Each group then reports their progress to the General Session. The "contract" written on paper with a carbonless copy allows both participants and planners to retain a copy. A sample contract format is included in Appendix B.

STRATEGIES FOR PROBLEM-SOLVING SESSIONS

Using a problem-solving approach allows for a number of possible alternatives and helps to gain the paticipants' commitment for their own proposals (Zimbardo, 1972). In addition, this approach allows participants to identify their "intentions" for initiating change for youngsters with disabilities both orally (in the presence of group members) and in writing. As Ajzen and Fishbein (1980) predict in their theory of reasoned action, a participant's **intention** to perform certain behaviors will be the actual determinant of their actions. Since both the staff and the participants have copies of the developed contract with professional and personal advocacy goals identified, follow-up evaluations can be conducted to assess the participants' success in accomplishing their initiatives.

This type of final session also reinforces the participant's internalization of the innovation, for as Havelock (1971) notes, for any innovation to be successful, the user must internalize it and invest energy and enthusiasm for it.

> The user will be more likely to internalize an innovation that he sees as his own, something that he has accepted by his **own free and deliberate choice** to meet his **own specific need**, and something that he has worked on himself to **adapt** to his own specific need (page 11-14).

12:15 pm SUMMARY AND CONCLUSION/WORKSHOP EVALUATION

Following the reports from individual and group deliberations of planned advocacy initiatives, initiatives are summarized and participants commended for their involvement and willingness to respond to the needs of youngsters with disabilties and their families.

1:00 pm ADJOURNMENT

E. Program Outcomes: During the workshops conducted across the country, participants formed professional and personal interdisciplinary alliances and networks. These alliances have resulted in planned advocacy initiatives at the local, state, and national levels to enhance the accessibility of health and health-related education services for the youngsters with disabilities in those regions. The faculty and staff have been extremely excited about the initiatives designed by these professionals across the country. Appendix B provides a summary sampling of these activities.

Perhaps most importantly, during the small-group working sessions in each of the regional workshops, participants consistently identified similar roles and responsibilities all health professionals should assume--whether or not they interact directly or consistently with youngsters who have handicaps. In addition, the roles and responsibilities mirrored those initially identified by the ASAHP's Advisory Council in planning the workshops. These roles and responsibilities are discussed in detail in **Unit 2** of the text.

Synthesizing the roles and responsibilities, however, five major responsibilities emerged repeatedly--across working groups and across regions. They include:

1. To communicate effectively with children and youth with disabilities and their families; i.e., to effectively adapt messages and actively listen to these youngsters and their families;
2. To understand state and federal legislation in order to assist families in solving problems related to the youngster's condition;
3. To recognize, accept, and implement one's professional responsibilities in identifying, referring, and advocating for youngsters with handicapping conditions and their families;
4. To help coordinate efforts of health, education, and related services; and
5. To develop and/or modify educational standards to create access rather than barriers to individuals with disabilities who wish to enter the health, education, and medical professions.

While these roles and responsibilities have been identified specifically for related-health professionals, their relevancy for other professionals who provide services to youngsters with disabilities and their families (e.g., special educators, regular educators, physicians, nurses, etc.) are obvious and are well-worth considering as all groups develop and evaluate pre- and in-service education programs.

SECTION TWO

CONTENT-RELATED INSTRUCTIONAL STRATEGIES

As noted earlier, this section provides instructional strategies and resource recommendations for each of the six units in the text:

Legal Foundations

Roles and Responsibilities

Communication

Issues in Identification

Referral, Coordination, and Management of Services

Advocacy

These strategies are provided to complement and supplement the content information contained in the text. Used together, these materials should assist planners in developing instructional programs which reflect the **cognitive**, **affective**, and **behavioral** dimensions of patient/client care. For easy referral, the recommendations are categorized by unit. The purpose and objectives for each unit are repeated from the text with suggestions provided for each of the following instructional strategies:

- **Discussion Questions**--provided to stimulate increased learner involvement with the issues addressed in the unit. The questions probe both technical and ethical issues, allowing for an exploration of knowledge, values, and ethics by both students and instructors. In some cases, an instructor may wish to use the questions to supplement other evaluation tools.

- **Learning Experiences and Exercises**--provided to involve learners in both the cognitive and experiential dimensions of the issues discussed in each of the units. Role modelling, group discussions, role playing, interviews, observations, research, and case-study approaches have been identified as appropriate and necessary instructional strategies which, when combined with the units, can help to achieve both a realistic and a holistic perspective in ethical and humanistic care giving. Case studies, which depict practical, clinical issues particularly are helpful in gaining the students' attention and commitment to their roles as professionals.

- **Strategies for Accessing Community Resource Persons**--provided to assist in identifying appropriate individuals with expertise relevant to the issues addressed in each unit. The information provided should assist instructors in identifying guest presenters and seminar faculty for instructional units as well as for appropriate referrals and additional resources for the unit.

  Community resource persons can contribute significantly in demonstrating for learners the relevance of the curriculum units to their professional competency as service providers.

- **Media Resources**--The suggested films, filmstrips, cassettes, and videotapes again can be used as stimulus material for discussion, providing relevant and realistic data for each of the instructional units. As noted in the previous sections, all media resource materials should be previewed and selected with care. Addresses for distributors follow the **Guide's** list of references.

- **Masters for Handouts and Overhead Transparencies**--provided for use with the instructional units. Sample materials for handouts and transparencies for all units are contained in Appendix C.

UNIT 1: LEGAL FOUNDATIONS

Overview: The health professional needs to know what services are required by law and regulation to meet the needs of children with handicapping conditions. In this unit, Josephine Barresi discusses Public law 94-142, Section 504, significant court cases, and variations in state law. Particular emphasis is given to the implications of these public policies for professionals in health and related fields.

Purpose: To review the development and requirements of public policy for the education of children and youth with handicapping conditions and the implications of this policy for health professionals.

Specific Objectives: At the conclusion of this unit, readers should be able to:

1. Discuss the development of federal and state public policy for the education of children and youth with handicapping conditions from an historical perspective, including legislation, litigation and regulation.

2. Identify the rights and protections contained in Public Law 94-142 (The Education for All Handicapped Children Act of 1975) and Section 504 of the Rehabilitation Act of 1973 for children and youth with handicapping conditions and their families.

3. Recognize the need to obtain current information about federal and state legislation and regulations affecting the education and related-health needs and rights of youngsters with disabilities.

4. Identify the differences that exist between federal and state policy and among the states regarding the provision of special education and related services to children and youth with handicapping conditions.

5. Identify their state's special education programs, policies, and procedures for providing services to children and youth with handicapping conditions and their families.

6. Discuss the implications of Public Law 94-142 on the scope of practice for all health professionals.

Discussion Questions:

1. How does Public Law 94-142 affect you and other members of your profession?

2. To what extent have your educational experiences provided you with the needed competencies to address the rights of persons with disabilities? What additional training and information do you and/or other members of your profession need to be better informed?

3. If you were a United States legislator, what policies would you recommend to ensure children and youth with handicaps receive appropriate health and education services? What would you propose as a state legislator?

4. What resources do you have when you observe or suspect that the rights of children with handicaps or their parents are being denied? What could you do in the following situations:

   As you are reviewing a child's health record, you notice he was fitted for a hearing aid but you have never seen him wearing one. His mother told you that he might need to repeat a grade in school due to poor marks.

   You know several children who are not receiving physical therapy, even though their Individualized Education Programs (IEPs) indicate they should be. The physical therapist, who is a friend of yours, told you that she had a full caseload already and the district would have to hire someone else.

5. How would you evaluate the effectiveness of the individualized education program (IEP), least restrictive environment, non-discriminatory assessment, and due process requirements as they apply to the education of children with handicaps?

6. If Public Law 94-142 or Section 504 were repealed, what would be the result?

7. What discrepancies have you identified between federal legislation (PL 94-142) and your state's laws which affect youngsters with handicapping conditions? What changes would you recommend (if any)? Justify.

Learning Exercises:

1. Schedule an interview with a state legislator, staff member, or your state advocate for persons with handicapps to discuss the special education law. Are any amendments being considered? How can the law be improved?

2. Interview parents who have youngsters with handicaps to get their perspective on the IEP process. How might the process be improved?

3. Meet with representatives of a private school for children with handicaps to determine how they (a) implement the IEP and other requirements of P.L. 94-142 and (b) coordinate with the local public education agency.

4. Through contacts with resource persons, identify the related service providers who must be certified by the state education agency to work with students with disabilities in the schools. Are they employed by the education agency or hired under a contractual agreement with another agency? How do their contractual arrangements affect the services they provide?

5. Interview the state or local director of special education to identify interagency agreements between the education agency and health and human service agencies as they affect the identification, referral, and provision of special education and related services to children with disabilities.

6. Interview adults with disabilities working in your college or community. What problems did they encounter in primary and secondary schools? What problems do they encounter now?

7. Participate in the exercises in **Everybody Counts!** (see Additional Readings) to experience simulations of having handicaps.

8. Obtain a copy of the code of ethics for your profession. Determine how each statement applies to the principles discussed in this Unit.

9. Interview state or local service agency personnel to determine the kinds of educational services provided in your state for youngsters with disabilities prior to the passage of P.L. 94-142.

Resource Persons: There are many people who can contribute to a lively presentation of the current political scene regarding state and/or federal legislation and the regulations affecting youngsters with disabilities, their families, and their providers. Speakers can be invited to provide up-to-the-minute information on federal statuatory or regulatory changes, on state laws or regulations, or review how the policies discussed in this unit have been implemented in a particular agency. Another approach is to invite resource persons to be interviewed by the trainees to clarify issues and obtain the perspectives of authorities. Resource persons for this unit include: (1) the director of your state Protection and Advocacy System (Text Appendix 6A), (2) a local or state director of special education (Text Appendix 1B), (3) a member of the education or human services staff from the Governor's office or state legislature, (4) a representative from a professional, parent, or consumer group who can speak about policies for the education of students with disabilities from their perspectives. (See list of organizations in Text Appendix 5B.)

Media Resources:

Exceptional Times: An Historical Perspective of Special Education. The Council for Exceptional Children. 16mm sound color film. Approximately 20 min. Price $250.00; members $212.50.

P.L. 94-142 Implementing Procedural Safeguards--A Guide for Schools and Parents. Produced by the Council for Exceptional Children in conjunction with the Children's Television Workshop. Contents: three sound filmstrips; three audio cassettes; discussion guide; ditto masters for duplication. Price $90.00; members $76.00.

Individualized Education Programs for Handicapped Children. The Council for Exceptional Children. Contents: three full-color sound filmstrips and a copy of A Primer on Individualized Education Programs for Handicapped Children. Price $65.00; members $55.25.

Transparency/Handout Masters: Included in Appendix C of this Guide are the following masters pertaining to Unit 1:

- The Education for All Handicapped Children Act (Public Law 94-142): Central Principles
- Procedural Safeguards of Public Law 94-142
- Purpose of Public Law 94-142
- Definition of "Special Education"
- Definition of "Handicapped Children"
- Definition of "Related Services"
- Definition of "Least Restrictive Environment"
- Individualized Education Program (IEP): Procedures
- Individualized Education Program (IEP): Contents

UNIT 2: ROLES AND RESPONSIBILITIES

Overview: Health professionals function in numerous roles in which they have contact with youngsters with disabilities or their families. Whether as health care provider, neighbor, relative, friend, or concerned citizen, the health professional has a role in identifying, referring, and advocating for these children. In this unit, authors Anthony Bashir and Carolyn Del Polito, discuss both the barriers to effective service delivery and the care provider's roles and responsibilties.

Purpose: To explore the roles and responsibilities of health professionals in identifying, referring, and advocating on behalf of children and youth with disabilities.

Specific Objectives: At the conclusion of this unit, readers should be able to:

1. Discuss the impact of Public Law 94-142 on the roles and responsibilities of all health professionals.
2. Identify the barriers to effective service delivery and the responsibilities of health and education professionals in developing solutions.
3. Describe the roles and responsibilities of individuals in the related-health professions with respect to the needs and rights of children and youth with disabilities, including:
    a. providing effective and competent services;
    b. using effective communication strategies;
    c. identifying, referring, and advocating for youngsters with disabilities and their families;
    d. understanding relevant local, state, and federal laws, regulations, and procedures; and
    e. cooperating and coordinating with other professionals in the delivery of health and education services.

Discussion Questions:

1. What are the barriers and constraints in your work/personal environments to achieving efficient, cost-effective services for persons with disabilities? What actions/strategies are available to you to improve the situation?

2. How can you help to create a more collaborative team atmosphere with the other professionals with whom you interact?

3. How has Public Law 94-142 impacted the roles and responsibilties of health professionals? How can the law be more responsive to the needs of related services providers?

4. What are your professional roles and responsibilities for youngsters with handicapping conditions and their families? How do these differ from those of service providers in other health professions?

5. What would you consider to be the **most important** responsibility you have for a youngster you suspect of having a handicapping condition?

Learning Exercises:

1. Identify two or three providers of services to youngsters with handicapping conditions from professions other than your own. Interview them to determine (a) their educational background and expertise, (b) their experiences in working with persons who have disabilities, and (c) their professional roles as team members in serving youngsters with handicaps.

2. Role-play an interaction with a health care provider (select a specialty area) in which you are the parent who has just learned your new baby has cerebral palsy. What are your concerns? Does the health professional provide you with sufficient information? Too much information? What emotions, attitudes, and values are present in the situation? Are there ethical dilemmas present? How can these be resolved?

3. Invite a teacher to lunch. Identify and discuss the teacher's concerns/problems/questions regarding the youngsters in class who have handicapping conditions. What assistance might you provide the teacher?

4. Interview three youngsters in the school system who have handicaps to determine their perceptions of themselves, their perceptions of how others see them, and their educational hopes for the future. What additional assistance do they require to achieve their full potential? What are your responsibilities in assisting them?

Resource Persons: For presentations to discuss the barriers to the delivery of services, persons with handicaps and their parents definitely are experts. Similarly persons representing the consumers (e.g., lawyers and protection and advocacy agency personnel) as well as administrators of educational and health care agencies (e.g., superintendents and clinical and hospital administrators) can be invited to share their perspectives on effective and efficient service provision. The appendices in Unit 5 of the text can help to identify appropriate first contacts, but do not hesitate to tap your own networks first.

Media Resources:

"The Community". The American Academy of Pediatrics' Inservice Training Project for Physicians Serving Handicapped Children, Module 4. 3/4" Color Videotape; 45 minutes. Instructor's Manual available.

A series of vignettes dealing with the barriers faced by persons with handicaps in the community. Addresses such issues as community attitudes, perceptions of young adults, perceptions of parents, physician's roles, and community resources.

Sharing the Experience . . . With Galvin. The Stanfield House. 16mm. Sound color film; 28 minutes. Price $385; Rental $35.

The film describes a near ideal situation when the birth of a handicapped child resulted in the hospital and community working closely with Galvin's parents and grandparents. Such issues as pre-natal tests and future children are explored in a very personal and intimate fashion.

Transparency/Handout Masters: Included in Appendix C of this Guide are the following masters for Unit 2:

- Barriers to the Delivery of Services
- Roles and Responsibilities of Health Professionals Serving Youngsters with Special Needs

UNIT 3: COMMUNICATION

Overview: The ability to convey information clearly, to listen actively, to adapt to verbal and nonverbal cues, and to build trusting and cooperative relationships with clients and colleagues is crucial to effective, coordinated service delivery. This unit, written by Carolyn Del Polito, examines these and other aspects of the health professional's competence as a communicator when providing education and related services to youngsters with disabilities. Barriers to communication effectiveness and strategies for enhancing effectiveness also are discussed.

Purpose: To understand the communication process, the professional's role in that process, and the implications of appropriate communication behaviors for the provision of health and education services to youngsters with disabilities and their families.

Specific Objectives: At the conclusion of this unit, readers should be able to:

1. Discuss the implications of communication competence for the professional's role in the provision of coordinated health and education services for youngsters with handicapping conditions and their families.
2. Identify and discuss the barriers to effective communication with clients, their families, colleagues in health and education, and others concerned with the delivery of health and education services to youngsters with handicapping conditions.
3. Recognize and discuss the influence of others' perceptions of the health professional's roles in identification, referral, and advocacy initiatives for youngsters with disabilities.
4. Discuss the impact children and youth with handicapping conditions can have on all family relationships and the implications for communication interventions.
5. Identify, promote, and implement appropriate, supportive communication strategies (verbal and nonverbal) when interacting with children and youth with handicaps, their families, and others concerned with the delivery of education and health-related services.
6. Identify and promote appropriate communication strategies to identify and use parents' knowledge and expertise in designing the youngsters' education and related-health program.

Discussion Questions:

1. How do you perceive a person with a physical impairment? Emotional/psychological impairment? Mental impairment? How did these perceptions and attitudes develop? How do they affect your communication with youngsters who have these impairments, with their families, and with their other service providers?

2. What conditions, other than attitudes, affect your communication with others? What strategies can you employ to improve your communication patterns?

3. What kinds of barriers do you create in your interactions with others during a team activity or group process? What strategies can you employ to improve the group's communication patterns and achieve better results?

4. How would you evaluate your listening skills? Under what conditions do you find yourself more frequently "tuning out"? What strategies can you employ to improve your personal and professional listening skills.

5. When interacting with a client/patient, what kinds of problem-solving skills do you use most often? To what extent can the client/provider interactions be improved by using a problem-solving approach? How will this approach affect the development of the treatment and/or educational program?

6. What strategies would you use to encourage reluctant parents to refer their child for diagnosis of a potential handicap?

Learning Exercises:

1. Use the handout **"Perception of Self and Others"** in Appendix C with a partner, each completing the chart before making comparisons. Compare person A's Column I with Person B's Column IV, A's II with B's III, etc. Identify the reasons for each other's perceptions. What new information did you learn about how you communicate about yourself (verbally and nonverbally)? What new information did you learn about your partner?

2. Use the handout, **"Active Listening"** in Appendix C, with a partner. Check your ability to use the reflective response technique (discussed in **Unit 3** of the text) to understand what your partner is communicating. Conclude with a discussion of how each of your behaviors changed during the process of the exercise and why.

3. Interview at least two parents of children with disabilities and two health or education professionals. Ask the parents to list

their feelings during meetings with professionals. Ask the professionals to list their feelings during meetings with parents. Compare the two lists. Interview questions:*

- "When I meet with professionals (parents), I feel. . ."
- "I wish professionals (parents) were more . . ."
- "I like it when professionals (parents) . . ."

4. Schedule an interview with a health administrator to determine the techniques he/she uses to resolve conflicts and solve problems in the clinical setting. Refer to **Unit 3** of the text and use the Strategy and Evaluation questions to both plan and assess the effectiveness of your interview.

5. Take a class in sign language. Practice communicating with others using only sign language. What are the limitations and advantages of using this mode of communication?

6. Review the Tips Section in **Unit 3** (Appendix 3C) on communicating with persons who have varying types of handicaps. In an exercise with two other persons, simulate a communication impairment (e.g., vision loss by using a blindfold; hearing loss by using ear plugs and soft or no talking; or a severe motor speech disorder by using machine-generated speech such as provided by "Speak and Spell" developed by Texas Instruments).

   In a role-play situation, one person should assume and simulate a person with a communication impairment, another acts as a friend, and the third person role plays one who is to be introduced by the friend. After an introduction, the three should make plans to go out together, arranging type of activity, date, time, place, and preferences regarding expenses. If possible, the three should try to follow their plans and go out together, maintaining and interacting with the impairment. What did each person learn from the exercise? How did each compensate in the communication transactions?

7. For your next report or presentation, use the strategy techniques suggested in **Unit 3** of the text for planning your presentation. With one (or more) person(s), schedule to use a videotape camera and playback equipment to practice the presentation. Use the evaluation questions (**Unit 3**, Text) to review your approach. What communication skills do you wish to improve? Design a plan for improvement and then in two or three months, repeat the exercise.

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*Adapted from "How to Get Services by Being Assertive" by the Coordinating Council for Handicapped Children, Dearborn, IL.

8. Visit and interview a family who has a child with a handicap, or request to observe a counseling session with such a family to identify the family's (parents and siblings): (a) concerns and questions regarding services for the youngster with the handicap, (b) concerns regarding their relationships and activities with one another, and (c) perspectives on the overall impact of having a family member with a handicapping condition.

Resource Persons: To assist in the design and training of the section on communication, there are persons with expertise in interpersonal communication who should be contacted. Local colleges and universities generally have faculty in departments of Speech Communication or Speech and Theatre who regularly teach courses in all aspects of human communication, including interpersonal communication, small-group communication, and persuasion. In some cases, the faculty members and/or counsultants may specialize in health-care communication. In addition, faculty members from psychology or counseling departments can be helpful as well. It will be important, however, to identify persons with expertise in communication theory and practice to ensure quality training programs in communication skills.

Other resource persons who can provide extremely relevant information about speech, language, and hearing impairments are educators, practitioners, and administrators in speech-language pathology and audiology as well as persons with those impairments. As identified in **Unit 5** Apendix 5A, any of your state's associations for persons with physical, mental, and psychological impairments also can be contacted for additional contacts and assistance.

Media Resources:

Empathy. Barnard, Barr, and Schumacher. American Association of Colleges of Pharmacy. 1981.

Includes a 30 minute videotape depicting 6 vignettes of practioner/patient interaction, and an instructor's manual containing student exercises, readings, and role playing suggestions. A loan of the kit can be arranged through any college of pharmacy in the country.

Sharing the Experience . . . With Peter. The Stanfield House. 16mm. Sound color film; 28 minutes. Price $385; Rental $35.

The story of a family with three sons. The middle son, Peter, is non-verbal and has severe mental retardation. The film shows the use of sign language with Peter and how this gives him the tools to communicate within the family and school. The concepts of

"Extend-a-Family" also is explored, pairing able-bodied youngsters with those who have handicaps. First Prize, 1979 International Rehabilitation Film Festival.

The Family. The American Academy of Pediatrics' Inservice Training Project for Physicians Serving Handicapped Children, Module 2. 3/4" color videotape; 45 minutes.

A series of vignettes, primarily dealing with physicians, but appropriate for all health professionals, on such issues as: informing parents of their child's handicap, reactions of children and families, impact on parents' relationships, impact on siblings, family adjustments to community perceptions, and parents' perceptions of the physician.

Transparency/Handout Masters: Included in Appendix C of this Guide are the following masters for Unit 3:

- The Communication Process
- Some Common Listening Problems
- Active Listening
- Levels of Empathy
- Defensive and Supportive Communication Climates
- Perception of Self and Other

UNIT 4: ISSUES IN IDENTIFICATION

Overview: Because of their early access to children, health practioners are in a unique position to recognize handicapping conditions in young children. In this unit, Anthony Bashir identifies the indicators of both high-risk and handicapping conditions. Emphasis is placed on the role of the health professional in the identification and screening process and in conducting non-discriminatory, multidisciplinary assessments of youngsters with disabilities.

Purpose: To explore the processes involved in the screening, assessment, planning, and review of educational and health-related services for children and youth with handicapping conditions.

Specific Objectives: At the conclusion of this unit, readers should be able to:

1. Identify the indicators of the handicapping conditions included in Public Law 94-142:

    a. Visual impairments
    b. Hearing impairments
    c. Orthopedic impairments
    d. Speech impairments
    e. Mental retardation
    f. Severe emotional disturbances
    g. Learning disabilities
    h. Other health impairments

2. Identify and monitor "high-risk" children consistent with their professional roles.

3. Promote accountable decision-making in the design of early indentification and intervention strategies for children and youth exhibiting handicapping conditions.

4. Discuss the roles and responsibilities of all health and education professionals in coordinating the identification and screening procedures and non-discriminatory, multidisciplinary assessments of youngsters with disabilities.

5. Recognize when referals for education and/or related-health service are necessary and describe the presenting problem(s) or concern(s) to the appropriate referral agency or qualified professional resource.

Discussion Questions:

1. Why is it important to monitor high-risk youngsters? In what situations would you likely be the first person to identify a youngster with a suspected impairment?

2. What instruments are available to you as a professional for early diagnosis? How have these instruments been validated?

3. How can you be sure that tests and assessment procedures do not discriminate against minority populations?

4. To what extent are the assessment regulations in your state compatible with those outlined in PL 94-142? How does your state handle the differences (if any)?

5. To what extent are members of your profession usually involved in the identification of handicapping conditions? What are your recommendations for improving the identification process and your professional role in the process?

6. In your experience, what are the strengths and weaknesses of using definitions or defining persons with handicapping conditions?

Learning Experiences:

1. Schedule a vist with a colleague in your profession to observe an initial evaluation of a new client. Discuss with him/her the procedures and instruments used in the process as well as the colleague's recommended follow-up treatment and/or program plans and referral procedures. Are they the same you would recommend? Why/Why not?

2. Schedule visits with two (2) colleagues in health professions other than your own to observe two initial evaluations of new clients. Discuss with them the procedures and instruments used as well as their follow-up procedures. To what extent could these initial evaluations been improved if a team of professionals conducted their evaluations at the same time.

3. Schedule an interview with the parents of a younster who has been recently identified as having a handicapping condition. Discuss the procedures used by the professionals, the parents' satisfaction with the procedures, and the parents' intentions to follow-through with the professional's recommendations.

4. Schedule a visit with an early childhood clinic or a University Affiliated Facility (UAF) and observe the procedures used in assessing a child suspected of having a handicapping condition. To what extent were team evalua-

tions and/or team decision-making strategies used before the final prognosis was determined?

5. Schedule at least one visit with a special educator in the school system to observe youngsters with a variety of disabilities, the educational programs available to them, and the education and social advancements they can achieve.

6. Discuss alternatives to standardized intelligence testing with someone familiar with assessment procedures for minority students. What are the strengths and weaknesses of such measures?

Resource Persons: The focus of the instructional unit will determine the number and kinds of disability experts to be invited. A person with one disability (e.g., hearing loss) does not know necessarily the constraints or problems faced by an individual with cerebral palsy and vice versa, and one individual should not be expected to speak for those with other disabilities. Special educators who have expertise in all the disability areas, however, would be appropriate resource persons if an overview of all areas is desired. For detailed specialization in one or more areas, on the other hand, the primary health specialist and a person with the particular disability should be involved.

Media Resources:

Appraisal of the Infant. United Cerebral Palsy Associations, Inc. Sound color videotape. 16mm. 27 minutes. Available on a rental basis for 3 days. $12.00.

Prepared to increase nursing knowledge and skill in early identification and appropriate referral of the atypical infant and his family.

The Doctor Talks To You About Cerebral Palsy. Soundworks, Inc. Audiocassette. 60 minutes. Price $9.95

Discussion by Leon Sternfeld, M.D. that presents complete facts and valuable advice about cerebral palsy, including causes, prevention, psychological and behavioral factors, helpful programs and new research.

Dr. Larry Silver: Lecture. The American Academy of Pedatrics, 15 minutes videotape, 1981.

This fifteen minute lecture deals with a review of current research finding about controversial treatment approaches for children with learning disabilities. In a straight-forward manner, Dr. Silver reviews pattern therapy, sensory integration approaches, optometric exercises, megavitamin therapy, the Feingold Diet, and other controversial approaches.

UNIT 5: REFERRAL, COORDINATION, AND MANAGEMENT OF SERVICES

Overview: The child with disabilities often has a number of interrelated health and education problems. This unit introduces the health professional to the health, education, human resource, and community agencies providing services to these children and their families. Jayn Wittenmyer discusses strategies for accessing these services on behalf of the child and family and collaborating with other service providers to achieve quality, coordinated, and comprehensive services.

Purpose: To explore appropriate strategies for referral, coordination, and management of health, education, and related services for youngsters with disabilities.

Specific Objectives: At the conclusion of this unit, readers should be able to:

1. Identify referral sources within their particular health agency or facility.
2. Identify local, state, regional, and national resources for services for children and youth with handicapping conditions and their families.
3. Identify and use existing networks of community, parent, and disabled consumer groups to assist and support parents and siblings of handicapped children and youth.
4. Use procedures for making referral for appropriate education and health-related services, consistent with professional roles.
5. Facilitate and promote cooperation with other health-related and education professionals in providing services to children and youth with disabilities.
6. Identify, use, and promote the use of effective follow-up and case management strategies to facilitate children and youth receiving appropriate services.
7. Facilitate the parents' active involvement throughout the referral process in such a way as to make the best use of their knowledge and expertise.

Discussion Questions:

1. What personal experiences have you had in identifying a service you needed for yourself (health care, financial aid, etc.)? What obstacles did you encounter and how did you overcome them?

2. If you had a choice between two health care providers, what factors would you consider in choosing one over the other? How would you obtain the information you needed to make a choice?

3. What would your functions be as a case manager in a rural area when there are few referral sources and little coordination among them?

4. How should you deal with a referral source that was not providing the expected and/or appropriate services?

5. As a practioner, how can you prevent duplication and/or gaps in services to youngsters with disabilities and their families?

6. What considerations, services, and referrals can health practitioners provide to help young children with handicapping conditions during the transition from a pre-school program to a school program and from a high-school program to a career?

7. What should you do if you learn that a child's handicap was identified at an early age by a health provider but the school is not using the information?

Learning Experiences:

1. Schedule a meeting with an intake worker from a local service agency to determine how a referral is processed in that agency.

2. Talk with parents to discover their experiences and satisfaction with local referral sources in obtaining services for children with disabilities.

3. Spend a day with a case manager to observe the problems, strategies for effectiveness, and logistics in the daily routine of coordinating services for persons with disabilities.

4. Visit a special education class and follow the daily schedule with one student to see how different health professionals interact with the special education teacher and the student.

5. Make a resource list of both generic and specialized services in your local community. Explain how you would disseminate this listing to parents of youngsters with disabilities in your community.

6. Contact the National Rural Network to identify local networks, organizations, and agencies concerned with the needs of youngsters with disabilities in rural areas. (Address: National Rural Project, Center for Innovation and Development, Murray State University, Murray, KT 42071)

7. Review the case histories in Appendix C to determine additional service needs and potential referrals. Design a plan for making the referrals, identifying activities to be completed, person(s) responsible, and time-lines.

Resource Persons: The type of individuals listed as resources in other units also could be resources for this section. State Protection and Advocacy Agency directors, representatives from parent and professional organizations, public agency officials, and practioners are examples. These persons can share their extensive knowledge of community and state services, both specialized and general; suggest ways to facilitate referral processing; and discuss coordination of services from a variety of perspectives.

In addition, it would be meaningful to invite representatives from two or three agencies to participate in a panel discussion concerning existing coordination problems. In choosing agencies, select those which would be expected to interact on behalf of children with handicapping conditions and clearly present the issues you wish addressed.

It will be important to invite agency personnel who will be willing to share valuable information regarding the agencies, including the solution strategies they might employ to improve interagency cooperation. Because state and federal agencies are governed by policies and procedures, the resource persons may not have the authority to implement the corrective strategies they discuss. Care should be taken, therefore, not to create a defensive atmosphere by being critical of the agency's services, but to assist in facilitating the recommended corrective strategies.

Media Resources:

EPSDT and Head Start. Chapel Hill Training - Outreach Project. Slide-tape presentation. $35.00.

Provides a brief overview of the relationship between the Early Periodic Screening Diagnosis and Testing (EPSDT) and Head Start federal programs; and how they can work together in providing needed health and medical services to the children of low-income families, including those with disabilities.

Comprehensive Services for Atypical Infants and Their Families - An Overview. United Cerebral Palsy Associations, Inc. 16 mm. Color and Sound. 17 minutes. 3-Day rental, $10.00.

Highlights the cognitive, psychosocial and medically-related needs of atypical infants, particularly those with multiple dysfunctions of organic origin, and provides a general overview of service programs for this group.

Adapted Equipment and Environments (Infants and Toddlers with Neuromotor and Related Disorders). United Cerebral Palsy Associations, Inc. 80 slides. Audiotape-script. 12 minutes. 3-Day rental, $7.50.

Several relatively simple equipment adaptations and two adapted environments are illustrated, with suggestions provided about their use.

Transparency/Handout Masters: Included in Appendix C. of this Guide are the following masters for Unit 5:

- Case Studies:

  A -- John
  B -- Dottie
  C -- Gertrude

- Referral Log
- Follow-Up Log
- Referral Form
- Release Form
- Agency Response Form

UNIT 6: ADVOCACY

Overview: Advocacy is used throughout this publication to mean facilitating a continuum of services for clients and their families: from listening to their needs and concerns to supporting and promoting legislation on their behalf. In this unit, Ethan Ellis discusses different models of advocacy, advocacy resources, and advocacy roles for health care providers.

Purpose: To clarify the advocacy needs of children and youth with handicapping conditions and the diverse roles health professionals may assume in the advocacy process.

Specific Objectives: At the conclusion of this unit, readers should be able to:

1. Identify and promote the advocacy needs of children and youth with handicaps.
2. Discuss the concept of "advocacy" and promote an advocacy role for health professionals.
3. Describe the different models of advocacy and their appropriate use by health professionals.
4. Identify existing or potential coalitions and independent groups with whom to effectively advocate on behalf of children and youth with disabilities.
5. Identify and utilize resources for effective advocacy appropriately.
6. Identify barriers to and solutions for effective advocacy.

Discussion Questions:

1. What has the term "advocacy" implied to you in the past? Has the definition changed for you after reading this unit, particularly in terms of persons with handicapping conditions? What impact can this revised definition have on your role as a health professional?
2. Describe the range or continuum of advocacy activities available to health professionals on behalf of children with disabilities. What are the advocacy roles of members of your profession?

3. What barriers have you encountered when advocating for youngsters with handicapping conditions? How can these barriers be resolved?

4. How might you implement the major principles of effective advocacy in your current professional role?

5. How might the different models of advocacy be used most effectively by members of your profession? Other health and education professions?

6. List all of your professional, social, and family affiliations which might be potential resources in advocating for youngsters with disabilities.

Learning Experiences:

1. It has been said that each of us is separated from every other person in the world by no more than four other common acquaintances, (i.e., "X" knows somebody who knows somebody who knows somebody who knows somebody who knows "Y"). It usually proves true and the connections often are even more direct, making it a powerful tool for advocacy. Test out this theory.

2. Imagine a situation in which it is important for you to create an opportunity to let a decision-maker know your views on an issue affecting children with disabilities directly. Recall the theory above and describe the chain of acquaintances you would employ to reach (1) your school board president, (2) your district's state legislator, (3) either of your state's senators, and (4) the Secretary of the U.S. Department of Education.

3. Special education regulations of most states can be obtained simply by writing to the Department of Education in care of the state Capitol. Obtain a copy of both your state's regulations and those of a neighboring state. Compare them in the following areas: (1) child-study team composition, (2) evaluation procedures, (3) classification procedures and categories, (3) due-process procedures. Evaluate which state more effectively protects the rights of youngsters with handicapping conditions in each of these areas.

4. Call or write to the office of your state and national professional association. Ask them for a list of their legislation priorities and the names and addresses of legislators in your state who have an important role in decisions affecting those priorities. Pick an issue you agree with and write to the legislator(s), expressing your opinion.

5. Identify the lobbyist for the Association for Retarded Citizens (ARC), United Cerebral Palsy Associations (UCPA), or other parent advocacy group in your state capitol and volunteer to assist him/her in the organization's next legislative campaign.

6. Contact the Protection and Advocacy (P&A) System in your state to find out when and where it is conducting rights training workshops for disability or parent groups. Volunteer to attend or assist.

7. Visit your State Protection and Advocacy Agency and ask to observe and follow the agency's activities and proceedings for one case. Within professional capacities, what could health and/or education service providers do to help alleviate the need for case/court action for this client?

Resource Persons: Most advocates set aside part of their time for community education, training in the legal rights of persons with disabilities, and response to specific questions on advocacy. Staff from Protection and Advocacy Systems, state parent groups such as the Association for Retarded Citizens (ARC) or the United Cerebral Palsy (UCP), Independent Living Centers, and volunteers from disability groups usually are available to answer specific questions, speak to groups, and participate in panel discussions around issues affecting persons with disabilities. In using such resources, it is important to identify the issue you wish addressed and the persons or groups it affects. If you want someone to speak to a group to which you belong, it is important to identify that group and its interests in disability issues. Most advocates have expanded networks and will be able to refer you to additional and/or more appropriate resources. Call the director of your state's Protection and Advocacy (P&A) System if you have no other place to start. He/she is used to such requests and is listed in the resource materials at the end of **Unit 6** in the text (Appendix 6A).

Media Resources:

Justice and the Art of Gentle Outrage. Southwest Films. 16mm. Color. 21 1/2 minutes. $171.48.

Illustrates an effective advocacy program. Narrated by George Kennedy. Developed under the Child Advocacy Project of the Association for Retarded Citizens.

Something Shared. Southwest Films. 16mm. Color. 14 1/2 minutes. $118.24.

An introduction to the concept of Citizen Advocacy.

Transparency/Handout Masters: Included in Appendix C of this guide is the following master for Unit 6:

- Principles of Effective Advocacy

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ADDITIONAL READINGS

Communication Education 24, March, 1976.

This issue of the journal presents articles on teaching the basic course in oral communication. There are two articles directly relevant to devising courses that stress the individual and his or her specific needs as they relate to communication.

Friedman, Paul G. Interpersonal Communication: Innovations in Instruction. Washington, D.C.: National Education Association, 1978.

Explores the theoretical bases for the study and practice of the human relations approach to interpersonal communication. It also contains instructional approaches, teaching strategies, and numerous classroom activities.

Friedrich, Gustav W. (Ed). Education in the 80s: Speech Communication. Washington, D.C.: National Education Association, 1981.

The twenty articles contained in this volume address curriculum issues in speech communication from grades K-12, with implications for all populations in all areas of communication. A good synthesis of current initiatives and future needs for all learners in speech communication.

Light, Harriet K. Organizing Inservice Training Workshops Guidelines NY: United Cerebral Palsy Association. Paperback. 64 pp. 1981. $2.50.

Ten steps that can be adapted by affiliates or outside agencies in order to plan and implement as useful and successful inservice training workshop.

Staff Development Handbook, A Resource for the Transiciplinary Process. NY: United Cerebral Palsy Association. Paperback. 51 pp. 1976. $3.50.

Explains the process as developed through the UCPA Collaborative Infant Project and its applicability to other age groups.

ADDRESSES FOR RESOURCES

American Academy of Pediatrics
P.O. Box 1034
1801 Hinman Avenue
Evanston, IL 60204

Chapel Hill Training-Outreach Project
Lincoln Center
Merritt Mill Road
Chapel Hill, NC 27514

Soutwest Film Laboratory
P.O. Box 21328
Dallas, TX 75211

The Council for Exceptional Children
1920 Association Drive
Reston, VA 22091

The Stanfield House
P.O. Box 3208
Santa Monica, CA 90403

United Cerebral Palsy Associations, Inc.
66 East 34th Street
New York, NY 10016

APPENDICES

APPENDIX A: **Survey and Evaluation Forms**

APPENDIX B: **Sample Planning and Conference Forms**

APPENDIX C: **Transparency and Handout Forms**

APPENDIX A

Survey and Evaluation Forms

- NEEDS ASSESSMENT QUESTIONNAIRE
- DAILY EVALUATION FORMS
- FINAL EVALUATION FORMS

ALLIED HEALTH CHILD-FIND AND ADVOCACY SURVEY

RESPONSE INSTRUCTIONS

Most of the questions can be answered by simply putting a check mark in the square or squares which identify what you consider the most appropriate response. It does not matter what type of pen or pencil you use. Disregard the numbers in parentheses. They are only for use in computer tabulation of the results. Again, thank you so much for your cooperation.

☐☐☐☐☐☐☐
(C 1-7)

1. WHICH OF THE FOLLOWING CATEGORIES BEST DESCRIBES YOUR PROFESSION? (CHECK ONLY ONE.) (C 11-12)

   1. Audiology................☐
   2. Medical Technology........☐
   3. Occupational Therapy......☐
   4. Physical Therapy..........☐
   5. Social Work...............☐
   6. Speech-Language Pathology.☐
   7. Dental Services...............☐
   8. Other Medical.................☐
   9. Mental Health (other than the professions listed above): ☐ ______________________________
   10. Other (Specify): ☐ ______________________________

2. WHICH OF THE FOLLOWING BEST DESCRIBES YOUR PRIMARY WORK SETTING? (CHECK ONLY ONE.)

   1. Educational Institution ....1☐ (C 13)
   2. Residential Facility...2☐
   3. Non-Residential Health-Care Facility........................3☐
   4. Other (Specify): ______________________________________4☐

3. HOW WOULD YOU DESCRIBE YOUR WORK LOCALE? (CHECK ONLY ONE.)

   1. Urban or Surburban...1☐ (C 14)
   2. Rural...2☐

4. ARE YOU A DIRECT SERVICE PROVIDER FOR CHILDREN AND YOUTH, EITHER HANDICAPPED OR NON-HANDICAPPED, OR DO YOU SUPERVISE OTHERS WHO PROVIDE DIRECT SERVICES? (CHECK ONLY ONE.)

   1. Direct Service Provider......................................1☐ (C 15)
   2. Supervisor..2☐
   3. Both..3☐

5. WHICH **BEST** DESCRIBES YOUR IMMEDIATE SUPERVISOR? (CHECK ONLY ONE.)

   1. He/she is in my own profession...............................1☐ (C 16)
   2. He/she is a physician...2☐
   3. He/she is a school administrator.............................3☐
   4. Other (Specify): ______________________________________4☐

6. DO YOU OR DOES ANYONE IN YOUR IMMEDIATE FAMILY HAVE A HANDICAPPING CONDITION?

   1. Yes...1☐ (C 17)
   2. No..2☐

7. HOW WOULD YOU DESCRIBE YOUR KNOWLEDGE OF THE EDUCATION FOR ALL HANDICAPPED CHILDREN ACT (PUBLIC LAW 94-142) ? (CHECK ONLY ONE.)

    1. Very Knowledgeable...1☐ (C 18)
    2. Somewhat Knowledgeable.....................................2☐
    3. Not at All Knowledgeable...................................3☐

8. WHICH OF THE FOLLOWING ACCURATELY REFLECTS YOUR EXPERIENCE WITH THE IMPLEMENTATION OF THE EDUCATION FOR ALL HANDICAPPED CHILDREN ACT (PUBLIC LAW 94-142)? (CHECK ONLY ONE.)

    1. It helps my professional efforts very much.................1☐ (C 19)
    2. It is somewhat helpful.....................................2☐
    3. It makes my professional efforts more difficult............3☐
    4. Does not apply...4☐

9. I WOULD LIKE MORE CLARIFICATION OF PUBLIC LAW 94-142 REGARDING (CHECK ALL THAT APPLY):

    1. My responsibilities in response to PL 94-142...............1☐ (C 20)
    2. Third-party payments and PL 94-142.........................1☐ (C 21)
    3. Individualized Educational Program (IEP's).................1☐ (C 22)
    4. Other (Specify): ____1☐ (C 23)

10. DOES YOUR STATE HAVE A MANDATE FOR PROVIDING SERVICES FOR PRE-SCHOOL HANDICAPPED CHILDREN?

    1. Yes..1☐ (C 24)
    2. No...2☐
    3. I don't know...3☐

11. CHECK ALL THOSE HANDICAPPING CONDITIONS WHICH YOU FEEL COMPETENT TO IDENTIFY AND REFER.

Handicapping Conditions of Children and Youth	Competent to Identify	Competent to Refer
1. Deaf-Blind	(C 25)☐	(C 26)☐
2. Hearing Impaired	(C 27)☐	(C 28)☐
3. Learning Disabled	(C 29)☐	(C 30)☐
4. Mentally Retarded	(C 31)☐	(C 32)☐
5. Multi-handicapped	(C 33)☐	(C 34)☐
6. Orthopedically Impaired	(C 35)☐	(C 36)☐
7. Seriously Emotionally Disturbed	(C 37)☐	(C 38)☐
8. Speech Impaired	(C 39)☐	(C 40)☐
9. Visually Impaired	(C 41)☐	(C 42)☐
10. Other Health Impaired	(C 43)☐	(C 44)☐
High-risk Children and Youth *	(C 45)☐	(C 46)☐

---

* Children or youths who are at risk of developing a handicap because of medical problems or environmental conditions (e.g., low birth weight, poor nutrition).

12. HOW IMPORTANT WERE EACH OF THE FOLLOWING IN DEVELOPING YOUR ABILITY TO IDENTIFY HANDICAPPED CHILDREN AND YOUTH?

	Very Important 1	Somewhat Important 2	Not at All Important 3	Does Not Apply 4	
1. Courses in your formal education	☐	☐	☐	☐	(C 47)
2. Clinical practicum (associated with your formal education)	☐	☐	☐	☐	(C 48)
3. Continuing education courses	☐	☐	☐	☐	(C 49)
4. On-the-job training	☐	☐	☐	☐	(C 50)
5. Early work experiences	☐	☐	☐	☐	(C 51)
6. Recent work experiences	☐	☐	☐	☐	(C 52)
7. Personal non-work experiences	☐	☐	☐	☐	(C 53)

13. HOW KNOWLEDGEABLE ARE YOU OF THE FOLLOWING DIAGNOSTIC AND TREATMENT SERVICES FOR HANDICAPPED CHILDREN AND YOUTH IN YOUR COMMUNITY?

	Very Knowledgeable 1	Somewhat Knowledgeable 2	Not at All Knowledgeable 3	
1. School services in general	☐	☐	☐	(C 54)
2. Non-school services in general	☐	☐	☐	(C 55)
3. Facilities and services in your place of employment	☐	☐	☐	(C 56)
4. Local clinical/facilities and services	☐	☐	☐	(C 57)
5. Local school facilities and services	☐	☐	☐	(C 58)

14. IF YOU SAW A CHILD WHO HAS A HANDICAP OR IS AT RISK OF DEVELOPING A HANDICAP BECAUSE OF MEDICAL PROBLEMS OR ENVIRONMENTAL CONDITIONS, WHICH OF THE FOLLOWING ACTIONS WOULD YOU MOST LIKELY TAKE? (YOU MAY CHECK MORE THAN ONE.)

1. Refer the child or youth for appropriate diagnostic and/or treatment services..................1☐ (C 59)
2. Discuss the problem with the parents and suggest appropriate diagnostic and/or treatment services..................1☐ (C 60)
3. Recommend treatment only within my area of expertise..................1☐ (C 61)
4. Bring the case to the attention of another professional in my work unit..................1☐ (C 62)
5. Bring the case to the attention of another professional outside my work unit..................1☐ (C 63)
6. Take no action since it is not my role to identify such problems.1☐ (C 64)
7. Does not apply; I would not be likely to encounter these children and youth..................1☐ (C 65)
8. Other (Specify): ________________________________ 1☐ (C 66)

15. IF YOU HAVE REFERRED HANDICAPPED CHILDREN OR YOUTH, HOW SATISFIED WERE YOU WITH WHAT WAS DONE FOR THOSE YOU REFERRED? (CHECK ONLY ONE.)

1. Very satisfied..................1☐ (C 67)
2. Somewhat satisfied..................2☐
3. Not at all satisfied..................3☐
4. Don't know what help was given..................4☐
5. Does not apply..................5☐

16. IF YOU ARE DISSATISFIED WITH WHAT IS BEING DONE FOR A CHILD OR YOUTH, WOULD YOU FOLLOW-UP WITH FURTHER ACTION?

1. Yes..1☐ (C 68)
2. No...2☐

IF YES, WHAT WOULD YOU DO? ______________________________________ (C 69-70)

____

17. HOW COMFORTABLE DO YOU FEEL DISCUSSING HANDICAPPING CONDITIONS WITH:

	Very Comfortable 1	Comfortable 2	Somewhat Comfortable 3	Uncomfortable 4	
1. Handicapped children and youth	☐	☐	☐	☐	(C 71)
2. Parents	☐	☐	☐	☐	(C 72)
3. Supervisor	☐	☐	☐	☐	(C 73)
4. Colleagues	☐	☐	☐	☐	(C 74)

18. HOW MUCH EXPERIENCE HAVE YOU HAD WORKING WITH HANDICAPPED CHILDREN AND YOUTH? (CHECK ONLY ONE.)

1. A great deal...1☐ (C 75)
2. Some...2☐
3. Little...3☐
4. None...4☐

☐☐☐☐☐☐☐
(C 1-7)

19. IN THIS QUESTION, WE ARE INTERESTED IN LEARNING (A) THE APPROXIMATE NUMBER OF HANDICAPPED CHILDREN AND YOUTH (BIRTH TO 21 YEARS) YOU HAVE EITHER SEEN OR COME IN CONTACT WITH IN A PROFESSIONAL SETTING DURING A TYPICAL MONTH, AND (B) THE APPROXIMATE NUMBER OF THESE CHILDREN AND YOUTH REFERRED FOR APPROPRIATE SERVICES.

Handicapping Conditions	Seen Approximate number of children and youth seen during a typical month	Referred Approximate number of children and youth referred for appropriate services during a typical month	Does not apply
1. Deaf-Blind	(C 11,12) ______	(C 13,14) ______	☐
2. Hearing Impaired	(C 15,16) ______	(C 17,18) ______	☐
3. Learning Disabled	(C 19,20) ______	(C 21,22) ______	☐
4. Mentally Retarded	(C 23,24) ______	(C 25,26) ______	☐
5. Multi-handicapped	(C 27,28) ______	(C 29,30) ______	☐
6. Orthopedically Impaired	(C 31,32) ______	(C 33,34) ______	☐
7. Seriously Emotionally Disturbed	(C 35,36) ______	(C 37,38) ______	☐
8. Speech Impaired	(C 39,40) ______	(C 41,42) ______	☐
9. Visually Impaired	(C 43,44) ______	(C 45,46) ______	☐
10. Other Health Impaired	(C 47,48) ______	(C 49,50) ______	☐
11. High-risk Children and Youth	(C 51,52) ______	(C 53,54) ______	☐

20. INDICATE ANY PROBLEMS IN YOUR WORK ENVIRONMENT WHICH MAKE IT DIFFICULT FOR YOU TO IDENTIFY AND REFER HANDICAPPED CHILDREN AND YOUTH.

____ (C 55-56)

____

21. WHICH OF THE FOLLOWING STATEMENTS REFLECT YOUR POSITION REGARDING ADVOCACY** FOR HANDICAPPED CHILDREN AND YOUTH? (CHECK ALL THAT APPLY.)

1. It is my professional responsibility to be an advocate for handicapped children and youth.................................1☐ (C 57)
2. It is my personal responsibility to be an advocate for handicapped children and youth.................................1☐ (C 58)
3. Any advocacy activities I initiate could jeopardize my job.......1☐ (C 59)
4. I am concerned about handicapped children and youth, but I would not know how to begin advocating for them.................1☐ (C 60)
5. It is not my role to be an advocate............................1☐ (C 61)
6. I would like more information on how to advocate for handicapped children and youth.................................1☐ (C 62)

22. CHECK ALL THOSE ADVOCACY ACTIVITIES IN WHICH YOU HAVE PARTICIPATED:

1. Regularly reading articles related to handicapping conditions....1☐ (C 63)
2. Participating in courses, workshops, or conferences regarding handicapping conditions.......................................1☐ (C 64)
3. Training other persons to identify handicapping conditions.......1☐ (C 65)
4. Giving presentations to local community groups..................1☐ (C 66)
5. Representing an individual family of a handicapped child or youth to obtain necessary services..............................1☐ (C 67)
6. Joining organizations which advocate for the rights of handicapped children and youth.................................1☐ (C 68)
7. Helping to develop public policy for handicapped children and youth..1☐ (C 69)
8. Actively participating in organizations which advocate for the rights of handicapped children and youth....................1☐ (C 70)
9. Writing articles/books regarding handicapped children and youth..1☐ (C 71)
10. Taking opportunities to advocate for handicapped children and youth in personal situations ....1☐ (C 72)
11. Other (Specify): ______________________________________1☐ (C 73)

23. IF YOU WOULD LIKE TO RECEIVE A SUMMARY OF THE SURVEY'S FINDINGS AND/OR FURTHER INFORMATION ABOUT THE ALLIED HEALTH CHILD-FIND AND ADVOCACY WORKSHOPS, PLEASE CHECK THE APPROPRIATE ITEM(S).

1. Please send me a copy of a summary of the survey's findings......1☐ (C 74)
2. Please send me information about the project's workshops.........1☐ (C 75)
3. Please send me information about the American Society of Allied Health Professions (ASAHP)......................................1☐ (C 76)

**For this survey advocacy is defined as facilitating a continuum of services (whether health or education-related) for handicapped children or youth.

ALLIANCES IN ADVOCACY FOR DISABLED CHILDREN AND YOUTH

Daily Feedback Form

The following questions ask for your reactions to today's sessions. Since this is the first of several planned workshops, your feedback is very important to us. In addition to circling your response, please share your comments with us.

Comments

Quality of Presentation

Poor 1 2 3 4 5 6 7 8 Excellent

Usefulness of the Presentation

Low Utility 1 2 3 4 5 6 7 8 High Utility

Complexity of the Content

Too Simple 1 2 3 4 5 6 7 8 Too Difficult

Quality of Group Interaction

Poor 1 2 3 4 5 6 7 8 Excellent

Amount of Group Interaction

Too Little 1 2 3 4 5 6 7 8 Too Much

Visual Aids or Media Used

Effective 1 2 3 4 5 6 7 8 Ineffective

Amount ot Time Allotted

Too Little 1 2 3 4 5 6 7 8 Too Much

Please list any related issues you feel should be covered during this session.

Additional Comments:

ALLIANCES IN ADVOCACY FOR DISABLED CHILDREN AND YOUTH

Final Workshop Evaluation

For this evaluation please consider the entire workshop as a whole and give us your general reactions. Your suggestions for improving the effectiveness of the workshops would be most appreciated. Scale: 5 = Outstanding; 4 = Very Good; 3 = Acceptable; 2 = Needs Improvement; 1 = Poor

			Comments
1.	Quality of the Workshop	1 2 3 4 5	
2.	Usefulness of the Workshop	1 2 3 4 5	
3.	Design of the Workshop	1 2 3 4 5	
4.	Relevancy of Topics Covered to Purpose of the Workshop	1 2 3 4 5	
5.	Appropriateness of Theory Presented	1 2 3 4 5	
6.	Appropriateness of Practical Information Presented	1 2 3 4 5	
7.	Appropriateness of Lectures Presented	1 2 3 4 5	
8.	Appropriateness of Small Group Discussion Sessions	1 2 3 4 5	
9.	Effectiveness of Speakers and Conference Leaders	1 2 3 4 5	
10.	Quality and Appropriateness of Films and Videotapes	1 2 3 4 5	
11.	Quality and Usefulness of Workshop Manual	1 2 3 4 5	
12.	Quality and Appropriateness of Facilities	1 2 3 4 5	
13.	Quality of Meals	1 2 3 4 5	
14.	Overall Personal Experience in the Workshop	1 2 3 4 5	

Open-Ended Evaluation Questions

To allow for your personalized responses to the curriculum, we are asking you to complete the following questions based on your experiences with this workshop.

1. Have your perceptions of handicapped children and youth changed because of your experiences in the workshop? If so, in what ways?

   Please identify those activities/events in the workshop which you believe produced these changes.

2. Because of your experiences in this workshop, what changes might occur in your work setting for providing services for disabled children and youth?

   Please identify those activities/events in the workshop which you believe will help to produce these changes.

3. What suggestions do you have for improving the workshop?

4. Regarding the identification, referral, and advocacy initiatives promoted during this workshop, is there additional information or strategies which you feel you still need? Please explain.

5. What were the primary benefits of this workshop for you?

6. What were the primary weaknesses of this workshop for you?

Additional Comments:

Thank you so much for completing these questionnaires. We sincerely appreciate your assistance and look forward to sharing the results with you.

APPENDIX B

Sample Planning and Conference Forms

- SAMPLE BUDGET
- CHECKLIST/PROGRAM PLAN
- SAMPLE AGENDA
- SAMPLE QUESTIONNAIRE
- SAMPLE CONTRACT FORMS

BUDGET ESTIMATES

The following budget reflects anticipated costs for a two-day workshop/seminar conducted in 1983-1984. Costs can be reduced depending on the area of the country in which the program is held and other available resources.

I. Consultant/Faculty: (Out-of-Region: Per-Person Costs)	
A. Travel: Airfare and Ground Transportation	$440.00
B. Per Diem @ $80/Day x 2 D	160.00
C. Honorarium @ $350/Day x 2 D	700.00
II. Resource Persons: (Local to State/Region: Per-Persons Costs)	
A. Travel	200.00
B. Per Diem @ $80/Day x 2 D	160.00
C. Honorarium @ $150/Day x 2 D	300.00
III. Materials/Supplies: (Participant Costs)	
A. Resource Text: *Alliances in Health and Education: Serving Youngsters with Special Needs*	15.00
B. Resource Manual: *Alliances in Advocacy for Disabled Children and Youth* (optional)	40.00
C. Miscellaneous: State Resource lists; Evaluation forms; Additional resource materials; Picture Profile, Badges; Folders/etc.	7.50
IV. Administrative Costs: Secretarial; Postage; Phone	300.00
V. Other:	
A. Equipment Rental @ $100-350/2 Days	________
B. Food Functions	
o Continental Breakfasts 2 @ $5.00	10.00
o Refreshment Breaks 5 @ $1.50	7.50
o Luncheon 1 @ $10.00	10.00

PLANNING

ACTIVITIES AND TIME-LINES

The following chart outlines the major activities which a planning committee will need to consider in preparing for a workshop, conference, or seminar. Target dates for completion of tasks and the persons responsible should be identified by the planning committee.

Target Date/ Person — **Major Planning Activities**

__________ 1. Identify Nominees/Participants

__________ 2. Identify and Contact Faculty

__________ 3. Finalize Curriculum and Instuctional Strategies

__________ 4. Identify and Contact Resource Persons

__________ 5. Identify and Obtain Resource Materials (print and non-print)

__________ 6. Complete Site Arrangements

a. Sleeping Room Accomodations:
- Guest Speakers/Resource Persons
- Participants
- Staff (if relevant)

b. Meeting Room Facilities (usually provided free by hotel/conference center if a meal function is involved)

Set-up:
- Round tables; seating 8-12 depending on group size, allows for participant interaction and sharing of ideas and resources

- Head table with microphone (if room is large) for opening presentations; lectures

Times/Space
- Pre-Study Session
- General Session
- Small Group Session
- Social Activities

Target Date/ Person   Major Planning Activities

__________ 7. Finalize Food Function Arrangements:
- Beverage Breaks
- Luncheon
- Social/Cocktails

__________ 8. Finalize Arrangements for Audio-Visual Equipment

- Type of Equipment
- Time Needed
- Costs (Borrow/Rental)

__________ 9. Mail Pre-Seminar Materials to Participants (See Appendix B for Sample)

Provide:
- Seminar Goal/Objectives
- Agenda
- Hotel Registration and Information
- Resource Materials (as appropriate)

Solicit:
- Resume or letter/statement of interests or concerns: to learn as much about individual participants as possible

- Resource Materials participants would like to share with others--request multiple copies when available/appropriate

__________ 10. Prepare/Ship Resource Materials to Conference Site

AMERICAN SOCIETY OF ALLIED HEALTH PROFESSIONS
ONE DUPONT CIRCLE, WASHINGTON, D.C. 20036 TELEPHONE: (202) 293-3422

PRESS RELEASE

______________________________ WINS SCHOLARSHIP FOR ADVOCACY WORKSHOP FOR DISABLED CHILDREN

______________________________ OF ______________________________
(Name) (Town)

____
(Title and Institution or Organization)

has been awarded a scholarship to participate in the American Society of Allied Health Profession's (ASAHP) fourth regional workshop on: "Alliances in Advocacy for Disabled Children and Youth."

The workshop which will be held December 3-5 at the Hyatt Regency Nashville in Nashville, Tennessee is part of a three-year effort bv ASAHP to prepare Allied Health professionals for leadership roles related to Public Law 94-142, the Education for All Handicapped Children Act of 1975.

The primary goal of the workshop is to facilitate communication and cooperation among Allied Health, Education, and Health professionals in providing services for children and youth with handicapping conditions. Participants, representing a variety of Allied Health professions, will explore the barriers impeding the delivery of appropriate services for these children through formal presentations and informal discussions with faculty, invited resource persons, and other highly competent participants.

Allied Health Child-Find and Advocacy Project
Carolyn M. Del Polito, Ph. D., Director

PRESS RELEASE (continued)

Topics to be addressed in the three-day workshop include: "Perspectives on the Law," "Roles and Responsibilities of Allied Health Professionals," "Issues in Diagnosis Assessment and Educational Planning," "Information Exchange and the Referral Process," "Communication Strategies," "Networking Strategies," and "Strategies for Effective Advocacy."

Included among the faculty are: Dr. Anthony Bashir of the Children's Hospital Medical Center, Boston; Ethan Ellis, New Jersey Department of the Public Advocate; Dr. Sally Pisarchick of the Inservice Instructional Research Center, Maple Heights, Ohio; Dr. John Wiemann, Department of Communication, University of California, Santa Barbara; Jayn Wittenmyer, Executive Secretary of the Wisconsin Council on Developmental Disabilities; and Dr. Carolyn M. Del Polito, Director of ASAHP's Allied Health Child-Find and Advocacy Project. These nationally known speakers will be supported by Resource persons knowledgeable about services for disabled children and youth in the Region.

The American Society of Allied Health Professions, located in Washington, D.C., is a non-profit professional organization whose membership consists of professional organizations, education institutions, and individuals devoted to Allied Health education, research, and service delivery. For additional information regarding the Society's activities, contact: Richard J. Dowling, Executive Director, American Society of Allied Health Professions, One Dupont Circle, Washington, D.C., phone: 202-293-3422.

ALLIANCES IN ADVOCACY FOR DISABLED CHILDREN AND YOUTH

Region VIII Workshop Agenda

Colorado, Montana, North Dakota, South Dakota,
Utah, Wyoming
May 20-22, 1982

Holiday Inn Denver Downtown
15th and Glenarm Place
Denver, Colorado 80202

PRE-STUDY SESSION ON PUBLIC LAW 94-142

THURSDAY

9:30 am PRE-WORKSHOP REGISTRATION

10:00 am STUDY SESSION ON PUBLIC LAW 94-142

Dr. Brian McNulty, Supervisor for Special Education Service Unit, Colorado Department of Education, Denver, Colorado

Dr. Nancy Schrant, Complaints Officer for Federal Programs, Office of the Commissioner, Colorado Department of Education, Denver, Colorado

- Clarification of the Legislation and Current Regulations
- Relationship of PL 94-142 to Section 504 of the Rehabilitation Act
- Implications of the Legislation for Allied Health Professionals

11:30 am Adjournment

ALLIANCES IN ADVOCACY FOR DISABLED CHILDREN AND YOUTH

Region VIII Workshop Agenda

Colorado, Montana, North Dakota, South Dakota,
Utah, Wyoming
May 20-22, 1982

Holiday Inn Denver Downtown
15th and Glenarm Place
Denver, Colorado 80202

THURSDAY

12:00 pm WORKSHOP REGISTRATION: PICTURE PROFILE OF PARTICIPANTS

1:00 pm OPENING ADDRESS: "Meeting the Challenge Through Alliances"

Dr. Carolyn M. Del Polito, Director, Allied Health Child-Find and Advocacy Project, American Society of Allied Health Professions

1:45 pm PERSPECTIVES ON THE LAW: RIGHTS OF CHILDREN AND YOUTH WITH WITH HANDICAPPING CONDITIONS

Moderator: Dr. Carolyn M. Del Polito

"The Current Political Climate," Mr. Ethan Ellis, Deputy Director, Office of Advocacy for the Developmentally Disabled, New Jersey Department for the Public Advocate

"The Parent's Response," Ms. Jayn Wittenmyer, Executive Director, Wisconsin Council on Developmental Disabilities, Madison, Wisconsin

"The Consumer/Client's Response," Ms. Theresa Preda, Executive Director, Holistic Approaches to Independent Living, Denver, Colorado

"The Health Provider's Response," Dr. Robert McCurdy, Director, Maternal and Child Health Services, Colorado Department of Health, Denver, Colorado

"The Audience Response," - Questions and Discussion

3:15 pm BREAK

THURSDAY (continued)

3:30 pm PERSPECTIVES ON GROWING UP DISABLED

"Implications for the Service Provider," Dr. Anthony Bashir, Speech Language Pathologist, Children's Hospital Medical Center, Boston, Massachusetts

"Consumer/Client's Response"

"Parent's Response"

"Educator's Response"

"Service Provider's Response"

4:15 pm PARTICIPANT INTRODUCTIONS (Small Groups Categorized by Profession)

5:00 pm INTRODUCTIONS TO ENTIRE AUDIENCE

6:30 pm Reception Sponsored by:

- Colorado Association for Speech and Hearing
- Colorado Chapter of the American Physical Therapy Association
- Occupational Therapy Association of Colorado

Dinner on Own

FRIDAY

8L00 am Continental Breakfast and Breakfast Movie

8:45 am BARRIERS TO THE DELIVERY OF SERVICE (Small Group Working Session)

10:15 am Break

10:30 am IMPLICATIONS FOR SERVICE PROVIDERS (Small Group Working Session)

12:00 noon LUNCHEON

Speaker: Dr. Joseph D. McInerny, Associate Director, Biological Sciences Curriculum Study, The Center for Education in Human and Medical Genetics, Louisville, Colorado

Topic: Genetics: Implications for the Allied Health Professional

2:00 pm FORECAST FOR THE FUTURE: ALLIANCES IN ADVOCACY

Critical Issues in Affecting Change

I. Knowledge of Rights and Needs of Disabled Youngsters

II. Advocacy Models and STrategies

FRIDAY (continued)

2:00 pm	FORECAST FOR THE FUTURE: ALLIANCES IN ADVOCACY (continued)
	III. Referral Sources and Strategies
	IV. Communication Skills and Strategies
2:20 pm	ADVOCACY MODELS
	Moderator: Mr. Ethan Ellis
3:00 pm	Break
3:15 pm	REFERRAL SOURCES AND STRATEGIES
	Moderator: Ms. Jayn Wittenmyer
4:00 pm	COMMUNICATION SKILLS AND STRATEGIES
	Moderator: Dr. Carolyn M. Del Polito
5:30 pm	ADJOURNMENT

SATURDAY

8:00 am	Continental Breakfast and Breakfast Movie
8:45 am	ADVOCACY:COMMITMENT AND IMPLEMENTATION
	I. "Strategies for Effective Advocacy"
	Moderator: Mr. Ethan B. Ellis
9:45 am	Break
10:00 am	ADVOCACY: COMMITMENT AND IMPLEMENTATION (continued)
	II. "Implementing Effective Advocacy Strategies"
	Moderator: Dr. Anthony Bashir
	• Personal Strategies
	• State Strategies
	• Professional Strategies
12:15 om	SUMMARY AND CONCLUSION/WORKSHOP EVALUATION
1:00 pm	ADJOURNMENT

Sample Questions for Workshop Discussion

Advocacy Questions

1. What is Advocacy?
2. How have advocacy activities changed in the past 10 years?
3. How do you overcome feelings of fear and lack of self-confidence in possible advocates?
4. How do you figure our appropriate incentives for change?
5. How do we interest people in advocacy roles?
6. How do you promote positive advocacy?
7. How do you advocate for children in rural areas?
8. Are there materials to help you become a better advocate?

Referral Questions

1. How do you develop a referral system?
2. How does a rural family link into referral services?
3. How do you cope with a source you have referred people to that is not living up to its responsibilities as a provider?
4. What do you do when you are working in an area, i.e., rural, when there are very few referral sources and they are not working together—How do you function as a case manager?
5. What are good tracking methods?
6. In the referral system how does the practitioner prevent overlapping and gaps?
7. How do you help to provide a transition from a pre-school program to a regular school program?
8. How do you cope with early identification by certain providers which is not transferred or utilized by the school?

Communication Questions

1. What are the most common barriers to effective communication?
2. What means can be taken to develop effective personal communication skills?
3. How do you deal with people who have no sensitivity to disability?
4. What techniques can leaders or perceived experts use to encourage people to take responsibility for themseleves?
5. Under burnout conditions, how does one effectively communicate?
6. How does one tell an administrator, physician, director of special education, etc., that what they are doing is inappropriate or detrimental to the child/person?

ALLIANCES IN ADVOCACY FOR DISABLED CHILDREN AND YOUTH CONTRACT

NAME: ____________________
ADDRESS: ____________________
____
ZIP: ____________ PHONE: ____________

REGIONAL WORKSHOP ATTENDED: ____________________
PROFESSIONAL ORGANIZATION MEMBERSHIP: ____________________
____

State Advocacy Goals	Date Completed	Professional Advocacy Goals	Date Completed	Personal Advocacy Goals	Date Completed

Comments:

SUMMARY OF REGIONAL WORKSHOP CONTRACT FORMS

PROFESSIONAL STATE ADVOCACY GOALS:

DISSEMINATION OF INFORMATION

- Public--newspapers/TV/radio
- Professional organizations--newsletters/journals
- ASAHP--Newsletters/ Journals/ Meetings
- Physicians--direct contact/AMA contact
- Legislators

ALLIANCES

- Create
- Seek
- Coordinate

EDUCATION

- Determine needs of patients/clients
- Implement changes in curriculum (schools)
- Initiate continuing education courses within professional organizations
- Promote in-service training in job settings
- Take professional development courses

LEGISLATION

- Disseminate information to legislators
- Use professional organizations to lobby
- Establish legislative committees

PROFESSIONAL ORGANIZATIONS

- Articles for newsletters/journals
- Meetings--workshops/presentations/panels/position papers
- ASAHP presentations
- Increase personal participation

WORK SITUATION

- Disseminate information to co-workers/employers
- Sensitize co-workers to issues
- Influence employers/supervisors
- Conduct professional peer reviews

ADVOCACY

- Act as resource person
- Encourage others to become advocates
- Develop resource lists
- Provide support services for children

PERSONAL ADVOCACY GOALS:

DISSEMINATION/INTEGRATION OF INFORMATION

- Professional organizations
- Legislators
- Educators
- Public
- Families
- Friends
- Community
- Students

ASAHP

- Build liaisons with professional organizations
- Promote presentations at annual meetings
- Support continuation of Advocacy Initiative

EDUCATIONAL SYSTEMS

- Provide information and resources
- Visit schools

LEGISLATION

- Write letters
- Promote PL 94-142

PROFESSIONAL ORGANIZATIONS

- Remain active
- Promote coalitions/liaisons/alliances
- Publish articles

WORK SITUATION

- Obtain advocacy information
- Promote in-service on advocacy

ADVOCACY

- Provide support services for children
- Act as resource persons
- Encourage others to become advocates (parents/children)
- Develop resource lists

FAMILIES

- Inform them of their rights
- Raise levels of awareness/responsibility

Contract Summaries

LEVEL OF KNOWLEDGE

- Seek agencies/services
- Review and use workshop manual
- Determine needs of patient

AWARENESS

- Increase political understanding
- Improve identification skills
- Develop priorities

APPENDIX C

Transparency and Handout Forms

UNIT 1: THE EDUCATION FOR ALL HANDICAPPED CHILDREN ACT: CENTRAL PRINCIPLES

- Procedural Safeguards of Public Law 94-142
- Purpose of Public Law 94-142
- Special Education: Definition
- Handicapped Children: Definition
- Related Services: Definition
- Least Restrictive Environment: Definition
- Individualized Education Program (IEP): Procedures
- Individualized Education Program (IEP):

UNIT 2: BARRIERS TO THE DELIVERY OF SERVICES

- Roles and Responsibilities of Health Professionals Serving Youngsters with Special Needs

UNIT 3: THE COMMUNICATION PROCESS

- Some Common Listening Problems
- Active Listening
- Levels of Empathy
- Defensive and Supportive Communication Climates
- Perception of Self and Other

UNIT 5: CASE STUDIES: A. Joan
B. Dottie
C. Gertrude

- Referral Log
- Follow-up Log
- Referral Form
- Release Form
- Agency Response Form

UNIT 6: PRINCIPLES OF EFFECTIVE ADVOCACY

THE EDUCATION FOR ALL HANDICAPPED CHILDREN ACT
(PUBLIC LAW 94 - 142)
CENTRAL PRINCIPLES

1. A FREE APPROPRIATE PUBLIC EDUCATION FOR ALL CHILDREN AND YOUTH WITH HANDICAPPING CONDITIONS REQUIRING SPECIAL EDUCATION AND RELATED SERVICES
2. COMPREHENSIVE, NONDISCRIMINATORY ASSESSMENT PROCEDURES
3. INDIVIDUALIZED EDUCATION PROGRAMS (IEPs)
4. PARENTAL INVOLVEMENT IN PLANNING AND DECISION MAKING
5. EDUCATION WITH NONHANDICAPPED CHILDREN TO THE MAXIMUM EXTENT APPROPRIATE: LEAST RESTRICTIVE ENVIRONMENT (LRE)
6. DUE PROCESS SAFEGUARDS FOR PARENTS AND CHILDREN
7. CONFIDENTIALITY OF RECORDS
8. FULL SERVICES GOAL BY 1980 FOR ALL CHILDREN AND YOUTH WITH HANDICAPPING CONDITIONS, AGES 3 - 21 YEARS

PROCEDURAL SAFEGUARDS OF LAW

PARENTS, GUARDIANS, OR SURROGATE PARENTS ARE GUARANTEED THE RIGHT TO:

1. EXAMINE RECORDS
2. OBTAIN INDEPENDENT EVALUATIONS
3. ASSIGN A SURROGATE PARENT
4. RECEIVE WRITTEN PRIOR NOTICE OF SCHOOL ACTIONS, IN THEIR NATIVE LANGUAGE

   (NOTE: REGULATIONS REQUIRE WRITTEN PERMISSION BE OBTAINED IN ADDITION TO NOTICE.)
5. PRESENT COMPLAINTS
6. RECEIVE AN IMPARTIAL DUE-PROCESS HEARING WITH FURTHER RIGHTS TO:
   - REPRESENTATION BY COUNSEL
   - PRESENT EVIDENCE
   - CROSS EXAMINE AND COMPEL THE ATTENDANCE OF WITNESSES
   - OBTAIN A WRITTEN OR ELECTRONIC RECORD
   - RECEIVE WRITTEN FINDINGS OF FACTS AND DECISIONS
   - APPEAL TO THE STATE AND
   - INITIATE CIVIL ACTION IN COURT.

THE CHILD REMAINS IN CURRENT EDUCATIONAL PLACEMENT DURING A HEARING UNLESS THE PARENTS AND SCHOOL AGREE OTHERWISE.

PURPOSE OF PUBLIC LAW 94-142

"IT IS THE PURPOSE OF THIS ACT

- TO ASSURE THAT ALL HANDICAPPED CHILDREN HAVE AVAILABLE TO THEM...A FREE APPROPRIATE PUBLIC EDUCATION WHICH EMPHASIZES SPECIAL EDUCATION AND RELATED SERVICES DESIGNED TO MEET THEIR UNIQUE NEEDS,

- TO ASSURE THAT THE RIGHTS OF HANDICAPPED CHILDREN AND THEIR PARENTS OR GUARDIANS ARE PROTECTED,

- TO ASSIST STATES AND LOCALITIES TO PROVIDE FOR THE EDUCATION OF ALL HANDICAPPED CHILDREN: AND

- TO ASSESS AND ASSURE THE EFFECTIVENESS OF EFFORTS TO EDUCATE HANDICAPPED CHILDREN."

SPECIAL EDUCATION

"SPECIAL EDUCATION" IS DEFINED IN P.L. 94 - 142 AS:

> "SPECIALLY DESIGNED INSTRUCTION, AT NO COST TO PARENTS OR GUARDIANS, TO MEET THE UNIQUE NEEDS OF A HANDICAPPED CHILD, INCLUDING CLASSROOM INSTRUCTION, INSTRUCTION IN PHYSICAL EDUCATION, HOME INSTRUCTION, AND INSTRUCTION IN HOSPITALS AND INSTITUTIONS."

HANDICAPPED CHILDREN

"HANDICAPPED CHILDREN" ARE DEFINED IN P. L. 94-142 AS THOSE YOUNGSTERS WHO ARE:

MENTALLY RETARDED, HARD OF HEARING, DEAF, ORTHOPEDICALLY IMPAIRED, OTHER HEALTH IMPAIRED, SPEECH IMPAIRED, VISUALLY HANDICAPPED, SERIOUSLY EMOTIONALLY DISTURBED, OR CHILDREN WITH SPECIFIC LEARNING DISABILITIES WHO, BY REASON THEREOF, REQUIRE SPECIAL EDUCATION AND RELATED SERVICES."

RELATED SERVICES

"RELATED SERVICES" ARE DEFINED IN P. L. 94 - 142 AS:

> "TRANSPORTATION, AND SUCH DEVELOPMENTAL, CORRECTIVE, AND OTHER SUPPORTIVE SERVICES (INCLUDING SPEECH PATHOLOGY AND AUDIOLOGY, PSYCHOLOGICAL SERVICES, PHYSICAL AND OCCUPATIONAL THERAPY, RECREATION, AND MEDICAL AND COUNSELING SERVICES, EXCEPT THAT SUCH MEDICAL SERVICES SHALL BE FOR DIAGNOSTIC AND EVALUATION PURPOSES ONLY) AS MAY BE REQUIRED TO ASSIST A HANDICAPPED CHILD TO BENEFIT FROM SPECIAL EDUCATION, AND INCLUDES THE EARLY IDENTIFICATION AND ASSESSMENT OF HANDICAPPING CONDITIONS IN CHILDREN."

LEAST RESTRICTIVE ENVIRONMENT

"EACH STATE MUST ESTABLISH PROCEDURES TO ENSURE THAT":

...TO THE MAXIMUM EXTENT APPROPRIATE, HANDICAPPED CHILDREN, INCLUDING CHILDREN IN PUBLIC OR PRIVATE INSTITUTIONS OR OTHER CARE FACILITIES, ARE EDUCATED WITH CHILDREN WHO ARE NOT HANDICAPPED, AND THAT SPECIAL CLASSES, SEPARATE SCHOOLING OR OTHER REMOVAL OF HANDICAPPED CHILDREN FROM THE REGULAR EDUCATIONAL ENVIRONMENT OCCURS ONLY WHEN THE NATURE OR SEVERITY OF THE HANDICAP IS SUCH THAT EDUCATION IN REGULAR CLASSES WITH THE USE OF SUPPLEMENTARY AIDS AND SERVICES CANNOT BE ACHIEVED SATISFACTORILY."

INDIVIDUALIZED EDUCATION PROGRAM: PROCEDURES

MEETINGS:

A MEETING MUST BE HELD WITHIN 30 CALENDAR DAYS OF A DETERMINATION THAT THE CHILD NEEDS SPECIAL EDUCATION AND RELATED SERVICES. (REGULATIONS 300.343)

PARTICIPANTS:

EACH MEETING MUST INCLUDE:

1. A REPRESENTATIVE OF THE PUBLIC AGENCY, OTHER THAN THE CHILD'S TEACHER, WHO IS QUALIFIED TO PROVIDE OR SUPERVISE THE PROVISION OF SPECIAL EDUCATION;

2. THE CHILD'S TEACHER;

3. ONE OR BOTH OF THE CHILD'S PARENTS;

4. THE CHILD, WHERE APPROPRIATE (20 USC 1401; 1A);

5. OTHER INDIVIDUALS AT THE DISCRETION OF THE PARENT OR AGENCY. (REGULATIONS 300.344); AND

6. CERTAIN EVALUATION PERSONNEL FOR A HANDICAPPED CHILD WHO HAS BEEN EVALUATED FOR THE FIRST TIME. (REGULATIONS 300.344).

INDIVIDUALIZED EDUCATION PROGRAM (IEP): CONTENTS

THE IEP FOR EACH CHILD MUST INCLUDE:

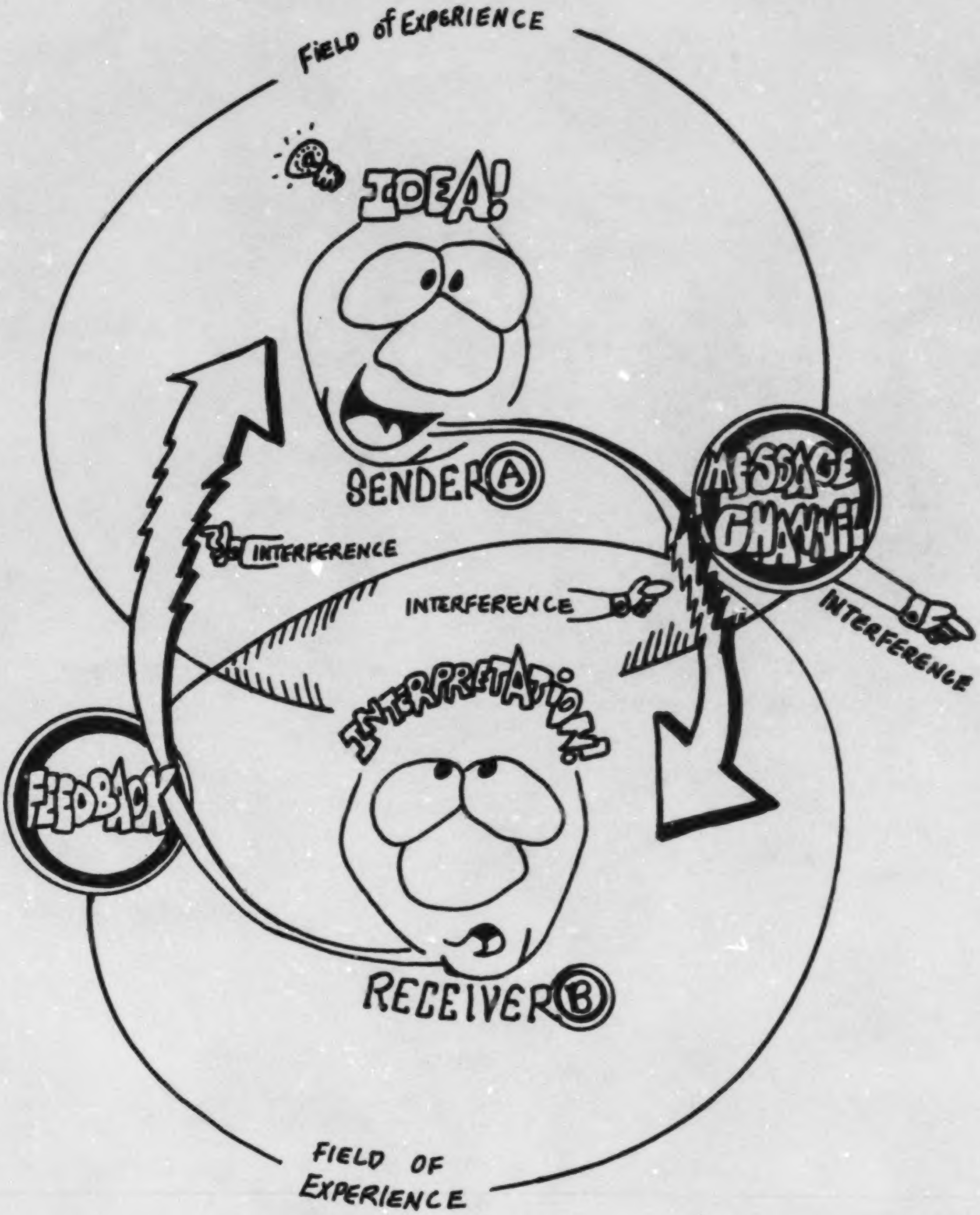
1. PRESENT LEVELS OF EDUCATIONAL PERFORMANCE;
2. ANNUAL GOALS;
3. SHORT TERM INSTRUCTIONAL OBJECTIVES;
4. THE SPECIFIC SPECIAL EDUCATION AND RELATED SERVICES TO BE PROVIDED;
5. THE EXTENT OF THE CHILD'S PARTICIPATION IN REGULAR EDUCATIONAL PROGRAMS;
6. PROJECTED DATES FOR INITIATION OF SERVICES;
7. THE ANTICIPATED DURATION OF THE SERVICES; AND
8. APPROPRIATE OBJECTIVE CRITERIA AND EVALUATION PROCEDURES AND SCHEDULE FOR DETERMINING, AT LEAST ANNUALLY, WHETHER THE SHORT-TERM INSTRUCTIONAL OBJECTIVES ARE BEING ACHIEVED.

BARRIERS TO THE DELIVERY OF SERVICES

- LEGAL AND REGULATORY PROCESSES
- SOCIETAL, CULTURAL, AND PROFESSIONAL ATTITUDES
- PROFESSIONAL PRACTICE AND TRAINING ISSUES
  - SCOPE AND LIMITS OF PRACTICE
  - CONTENT KNOWLEDGE AND TECHNICAL EXPERTISE
  - ETHICAL RESPONSIBILITIES
- COMMUNICATION EFFECTIVENESS
  - INTERPERSONAL INTERACTIONS WITH COLLEAGUES, CLIENTS, AND FAMILIES
  - INTERPROFESSIONAL INTERACTIONS WITH COLLEAGUES AND OTHER PROFESSIONALS IN HEALTH AND EDUCATION
- PROGRAMMATIC OPTIONS
- CONTINUITY OF CARE ISSUES

ROLES AND RESPONSIBILITIES OF HEALTH PROFESSIONALS SERVING YOUNGSTERS WITH SPECIAL NEEDS: SUMMARY

- TO RECOGNIZE AND ACCEPT THE NEEDS AND RIGHTS OF YOUNGSTERS WITH HANDICAPPING CONDITIONS.
- TO UNDERSTAND STATE AND FEDERAL LEGISLATION IN ORDER TO ASSIST FAMILIES IN SOLVING PROBLEMS RELATED TO THE CHILD/YOUTH'S CONDITION.
- TO PROVIDE EFFECTIVE AND COMPETENT SERVICES TO INDIVIDUALS WITH DISABILITIES AND THEIR FAMILIES AS APPROPRIATE TO ONE'S PROFESSION.
- TO RECOGNIZE AND ACCEPT ONE'S PROFESSIONAL RESPONSIBILITIES IN IDENTIFYING, REFERRING, AND ADVOCATING FOR YOUNGSTERS WITH DISABILITIES AND THEIR FAMILIES.
- TO DEVELOP AND USE EFFECTIVE COMMUNICATION STRATEGIES.
- TO HELP COORDINATE THE EFFORTS OF HEALTH, EDUCATION, AND RELATED SERVICE PROFESSIONS TO MEET THE NEEDS OF YOUNGSTERS WITH HANDICAPPING CONDITIONS.
- TO HELP DEVELOP AND/OR MODIFY EDUCATIONAL STANDARDS TO CREATE ACCESS RATHER THAN BARRIERS TO INDIVIDUALS WITH DISABILITIES WHO WISH TO ENTER THE HEALTH AND EDUCATION PROFESSIONS.


FIELD of EXPERIENCE
IDEA!
SENDER Ⓐ
MESSAGE CHANNEL
INTERFERENCE
INTERFERENCE
INTERFERENCE
INTERPRETATION!
FEEDBACK
RECEIVER Ⓑ
FIELD OF EXPERIENCE

THE COMMUNICATION PROCESS
Communications Skills, Inc.

SOME COMMON LISTENING PROBLEMS*

1. VIEWING A TOPIC AS UNINTERESTING.
2. CRITICIZING A SPEAKER'S DELIVERY INSTEAD OF THE MESSAGE.
3. GETTING OVERSTIMULATED OR EMOTIONALLY INVOLVED.
4. LISTENING ONLY FOR FACTS.
5. PREPARING TO ANSWER QUESTIONS OR POINTS BEFORE FULLY UNDERSTANDING THEM.
6. WASTING THE ADVANTAGES OF THOUGHT SPEED OVER SPEECH SPEED.
7. TRYING TO OUTLINE EVERYTHING.
8. TOLERATING OR FAILING TO ADJUST TO DISTRACTIONS.
9. FAKING ATTENTION.
10. LISTENING ONLY TO WHAT IS EASY TO UNDERSTAND.
11. ALLOWING EMOTIONALLY-LADEN WORDS TO INTERFERE WITH LISTENING.
12. PERMITTING PERSONAL PREJUDICES OR DEEP-SEATED CONVICTIONS TO IMPAIR COMPREHENSION AND UNDERSTANDING.

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*from Larry L. Barker, Listening Behavior, N. J.: Prentice Hall, 1971

ACTIVE LISTENING

One of the most important skills in getting to know another person is listening. In order to get a check on your ability to understand what your partner is communicating, the two of you should use the Reflective Response Technique.

Decide which one of you will speak first.
The first speaker is to carry on and complete the following item in two or three sentences:
When I think about the future, I see myself . . .

The second speaker repeats in his/her own words the statement that the first speaker has just said. The first speaker must be satisfied that he/she has been heard accurately.

The second speaker then completes the item in two or three sentences. The first speaker paraphrases what the second speaker just said, to the satisfaction of the second speaker.

. . . .

At this point discuss with your partner what you have learned about yourself as a listener. From here on it is important that both of you try to listen and understand one another as fully as possible, If at any point either of you feels this is not happening, you should stop. Try to determine why you have stopped communicating, discuss the situation as fully as possible and then continue.

. . . .

1. I am happiest when . . .
2. When I am alone I usually . . .
3. In large groups I usually . . .
4. I believe in . . .
5. The thing that turns me off the most is . . .
6. I love . . .
7. The thing that turns me on the most is . . .

. . . .

Have a two or three minute discussion about this experience so far.
Try to cover the following points:
How well are you listening?
How open and honest have you been?
How eager are you to continue this interchange?
Are you getting to know each other?

. . . .

8. The emotion I find most difficult to express is . . .
9. My strongest point is . . .
10. Expressing feelings makes me feel . . .
11. My weakest point is . . .
12. Getting to know new people is . . .

LEVELS OF EMPATHY

LEVEL I: MAXIMUM UNDERSTANDING THROUGH SOCIAL SENSITIVITY

A. UNDERSTANDING THE SPEAKER'S PERCEPTUAL WORLD

- ATTITUDES
- VALUES
- BELIEFS
- KNOWLEDGE
- CULTURE
- SOCIAL SYSTEM
- PAST EXPERIENCE
- FUTURE EXPECTATIONS

B. UNDERSTANDING OUR OWN PERCEPTUAL WORLD--SELECTIVE PERCEPTION

C. UNDERSTANDING THE CONTENT COMMUNICATED--WHAT IS BEING SAID?

D. UNDERSTAND THE FEELINGS COMMUNICATED--HOW IS THE MESSAGE BEING SAID?

LEVEL II: CONFIRMATION OF UNDERSTANDING THROUGH ACTIVE LISTENING

A. ATTENTION DURING COMMUNICATION

1. NONVERBALLY: ATTENTIVE POSTURE, HEAD NODS, EYE-CONTACT, FACIAL EXPRESSIONS
2. VERBALLY: VOCALIZATIONS WHICH INDICATE YOU'RE KEEPING UP WITH THE SPEAKER AND INTERESTED IN THE INFORMATION COMMUNICATED

B. REFLECTION OF MAXIMUM UNDERSTANDING OF OTHER'S IDEAS: VERBALLY AND NONVERBALLY

C. REFLECTION OF MAXIMUM UNDERSTANDING OF OTHER'S FEELINGS: VERBALLY AND NONVERBALLY

DEFENSIVE AND SUPPORTIVE COMMUNICATION CLIMATES

DEFENSIVE BEHAVIOR: behavior which occurs when an individual perceives threat or anticipates threat.

Defensive behavior leads to defensive listening and produces postural, facial, and verbal cues which raise the defense levels of the orginial communicator.

Increases in defensive behavior have been found to correlate positively with losses in efficiency in communication.

DEFENSIVE CLIMATES	SUPPORTIVE CLIMATES
1. Evaluation	1. Description--genuine requests for information.
2. Control	2. Problem-Orientation--collaborate on seeking solution to problem
3. Strategy--hidden motivation	3. Spontaneity--straightforward and honest
4. Neutrality--little warmth or concern for the other person	4. Empathy--respect for worth of the other person
5. Superiority	5. Equality--mutual trust & respect
6. Certainty--dogmatic	6. Provisionalism--willing to experiment and investigate issues

---

from Jack R. Gibb, "Defensive Communication", Journal of Communication, Volume XI, No. 3 (September, 1961), pp. 141-148.

PERCEPTION OF SELF AND OTHER

Complete the chart below, indicating how you see yourself, how your partner sees you, how you see your partner, and how your partner sees him/herself on the factors listed according to the following continuum.

1	2	3	4	5	6	7
Never or Almost Never True	Usually Not True	Sometimes But Infrequently True	Occasionally True	Often True	Usually True	Always or Almost Always True

	I I See Me	II Other Sees Me	III I See Other	IV Other Sees Self
1. Self-Reliant				
2. Yielding				
3. Helpful				
4. Defends Own Beliefs				
5. Cheerful				
6. Moody				
7. Independent				
8. Shy				
9. Conscientious				
10. Athletic				
11. Affectionate				
12. Theatrical				
13. Assertive				
14. Flatterable				
15. Happy				
16. Strong Personality				
17. Loyal				
18. Unpredictable				

PERCEPTION OF SELF AND OTHER

	I I See Me	II Other Sees Me	III I See Other	IV Other Sees Self
19. Forceful				
20. Feminine				
21. Reliable				
22. Analytical				
23. Sympathetic				
24. Jealous				
25. Supportive				
26. Has Leadership Abilities				
27. Sensitive to Others' Needs				
28. Truthful				
29. Willing to Take Risks				
30. Understanding				
31. Secretive				
32. Makes Decisions Easily				
33. Compassionate				
34. Sincere				
35. Self-Sufficient				
36. Eager to Soothe Hurt Feelings				
37. Conceited				
38. Dominant				
39. Soft-Spoken				
40. Likable				
41. Masculine				
42. Warm				
43. Solemn				
44. Willing to Take a Stand				

PERCEPTION OF SELF AND OTHER

	I I See Me	II Other Sees Me	III I See Other	IV Other Sees Self
45. Tender				
46. Friendly				
47. Aggressive				
48. Gullible				
49. Inefficient				
50. Acts as a Leader				
51. Childlike				
52. Adaptable				
53. Individualistic				
54. Does Not Use Harsh Language				
55. Unsystematic				
56. Competitive				
57. Loves Children				
58. Tactful				
59. Ambitious				
60. Gentle				
61. Conventional				
62. Speaks Freely About His/Her Feelings				
63. Defensive				
64. Accepts Others' Ideas				
65. Responsive to messages				

CASE STUDY A

John is a bright, highly social six-year-old whose birth defects have resulted in a severe speech problem which may be affecting his adjustment in school. He has associated visual, hearing, and motor problems. The following observations were made by the Multiclinic Treatment Team.

Psychology: John's teacher indicated that in the classroom he evidenced difficulty in attending. He is highly distractable, wanders around the room visiting with friends, and does not work well independently. John's father stated that there were no psychological problems with John, and that problems his teacher reports are a function of John's age.

Audiology: John has a history of middle ear problems and accompanying hearing loss, beginning approximately at age two or three.

Genetics: John's syndrome can be defined as a median cleft face syndrome which can be seen in the face as hyperterlorism, cleft lip, palate, and nasal groove defects. This syndrome is usually sporadic.

John's father, Tom, was interviewed about the family history. Since Tom was adopted, he has no information about his side of the family. No incidence of cleft palate or similar facial abnormalities were recorded on the mother's side of the family. John's syndrome, therefore, is most likely a sporatic incident, with little risk of recurrence in other offspring of these parents.

Occupational Therapy: John was reported by the teacher to "need improvement in skills like handwriting, coloring, cutting, and pasting." In occupational therapy, therefore, he was given several tests to evaluate his fine-motor coordination and other neurological tests relating to fine-motor coordination. Other tests given to John indicated some problems with motor planning, i.e., knowing where and when to move his limbs, that would contribute to the gross motor problem.

Speech Pathology: John's speech is unintelligible with a significant degree of hypernasality and nasal emission (due to escape of air through the nasal passageway) and misarticulation of several phonemes.

CASE HISTORY B

Dottie is a 26 month-old girl living with her parents and 3 1/2 year-old sister in a rural area. She has cerebral palsy, spastic quadriplegia with athetosis. She is an intelligent, nonverbal child who expresses herself with her eyes, gestures, and a few sounds.

Her sister has been throwing temper tantrums the past 6 months. Dottie's father has been extremely helpful in adapting and building equipment for Dottie and she is rapidly acquiring new skills in the area of communication.

At age 11 months, Dottie was seen in the Cerebral Palsy Diagnostic and Evaluation Clinic. Members of the evaluation team included neurodevelopmentally-trained occupational, physical, and speech therapists, a pediatric neurologist, pediatric orthopedic surgeon, opthalmologist, and audiometrist. The team was headed by a pediatrician who specialized in cerebral palsy.

A neurodevelopmentally-trained occupational therapist who provides therapy and support to the family in the home between clinical visits also was present with the family during diagnostic and follow-up visits. The home therapist visited the family within a week following the initial evaluation to answer questions and establish a schedule for visits. During the past 15 months, the therapist has shown and assisted the parents with:

- handling and positioning techniques to allow increased movement and improved functions;
- feeding skills and techniques to facilitate oral development and oral motor control;
- rolling with rotation skills; and
- suggestions for sitting and standing stabilization.

CASE STUDY C

Gertrude is 20 years-old and has mild-high moderate mental retadation. She lives at home with her parents in a rural area, seventy miles from an urban area. She first came to the attention of the county social services agency due to her drinking, promiscuity, and her involvement in a series of thefts. She was in jail until the trial, found guilty, placed on probation, and returned to live with her parents.

Gertrude is able to speak, take care of herself, and go into the community with supervision. She loves records and money. She has been sexually active since age 15 with a variety of men. Gertrude's parents are concerned but are conservative and have taken no steps to prevent pregnancy.

Gertrude's parents contacted the local social services department who indicated they had no suggestions to solve these problems. The county social services agency stated that they had a waiting list at the guidance clinic for counseling. The clinic is seventy miles away.

AGENCY REFERRAL AND FOLLOW-UP LOG
Step 1
REFERRAL PROCESS

RECIPIENT	AGENCY AND CONTACT PERSON	SERVICE REQUESTED	REFERRAL METHOD	REFERRAL DATE	COMMENTS

AGENCY REFERRAL AND FOLLOW-UP LOG
Step 2
FOLLOW-UP PROCESS

RECIPIENT	AGENCY	DATE OF INITIAL CONTACT	NO. OF DAYS TO CONTACT	DATE OF SERVICE DELIVERY	NO. OF DAYS TO DELIVERY	COMMENTS OR QUALITY OF SERVICE

REFERRAL FORM

Date ______________ From ________________________
(Name)

To ________________________ ________________________
(Agency) (Agency)

Atten ________________________ ________________________
(Address)

____
(Telephone)

Child's Name ____

Child's Sex __________________ Child's DOB __________________

Reasons for Referral/Service Desired ____________________________

____

____

____

Test Results, Observed Behavior, Professional Concerns ________

____

____

____

____

____

Signature ____________________________

Position ____________________________

RELEASE FORM

Date ______________________________

TO WHOM IT MAY CONCERN:

This is to authorize ____

to forward all records concerning testing, academic performance, health information and diagnosis, psychological evaluations and other information as listed, ____

____

____

____

for my child ____

These records are to be sent to: ____________________________________

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Signature of Parent or Guardian

AGENCY RESPONSE FORM

Date:____________________________________

TO:_______________________________(Name of Agency and Contact)

FROM:_____________________________(Health Practitioner)

RE:______________________________ __________________________
Client's Name Services Requested

As stated in the enclosed referral form, I am referring____________ _______________________ for __________________________________.

I feel that this child needs immediate attention and hope you will be able to make an initial contact/intake appointment within ten (10) days. Please return the bottom portion of this form for our records. Thank you.

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Return to ____________________________
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Client:____

Date of Initial Contact/Intake Appointment:______________________

Services Rendered and Dates of Service Delivery:___________________
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Date______________________ Signed____________________________
Agency____________________________

PRINCIPLES OF EFFECTIVE ADVOCACY

1. FIND OUT HOW DECISIONS ARE MADE WITHIN THE SYSTEM AND WHO MAKES THEM.
2. KNOW AS MUCH AS YOU CAN ABOUT DECISION MAKERS AND WHAT MAKES THEM TICK.
3. TREAT EACH ADVOCACY EFFORT AS A UNIQUE EVENT.
4. DON'T ASSUME THAT ANYBODY KNOWS ANYTHING, BUT NEVER TREAT THEM AS IF THEY DON'T.
5. INVOLVE THE CHILD WITH A DISABILITY AND HIS OR HER PARENTS IN THE DECISIONS FOR WHICH YOU ADVOCATE.
6. PARENTS HAVE A RIGHT TO BE WRONG . . . WITHIN VERY BROAD LIMITS.
7. KNOW YOUR LIMITS.